DOCUMENT RESUME

ED 436 032 EC 305 774

AUTHOR Blake, Ellen M., Comp.; Prouty, Robert W., Comp.; Lakin, K. Charlie

TITLE Reinventing Quality: 1995 Sourcebook of Innovative Programs for Quality Assurance and Quality Improvement of Community Services. Report #45.

INSTITUTION Minnesota Univ., Minneapolis. Research and Training Center on Community Living.

SPONS AGENCY Administration on Developmental Disabilities (DHHS), Washington, D.C.; National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.

PUB DATE 1995-07-00

NOTE 150p.

CONTRACT 90DD0180; H133B80048

AVAILABLE FROM Publications Office, Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive, SE, Minneapolis, MN 55455. Tel: 612-624-4512.

PUB TYPE Guides - Non-Classroom (055) -- Reference Materials - Directories/Catalogs (132)

EDRS PRICE MF01/PC06 Plus Postage.

DESCRIPTORS Advocacy; *Community Programs; *Delivery Systems; *Developmental Disabilities; Evaluation Methods; Group Homes; Networks; Professional Development; *Program Descriptions; *Program Evaluation; Program Guides; *Program Improvement; Resource Materials; State Programs; Technical Assistance

ABSTRACT

This sourcebook profiles approximately 80 programs that support the redefinition, assessment, and/or enhancement of quality in community services for individuals with developmental disabilities. Direct service programs, however, are not included. The programs and activities described are subsumed under the following broad categories: (1) statewide information and evaluation systems; (2) service agency development; (3) system-wide quality enhancement; (4) values infusion; (5) consumer and citizen monitoring; (6) community relationship building; (7) technical assistance; (8) personnel training and professional development; (9) advocacy training and support for individuals and families; (10) best practices; (11) quality assurance in Medicaid Community-Supported Living Arrangements programs; and (12) networking. Each entry begins with a statement of the type of program profiled and then includes information on the area served, the contact person, a description of the program, and a telephone number for additional information. The sourcebook opens with a paper on improving quality in community services for individuals with developmental disabilities, entitled: "Searching for Quality in the Crooked Map Zone" by John O'Brien. (CR)

Reproductions supplied by EDRS are the best that can be made
from the original document.

ED 436 032

UNIVERSITY OF MINNESOTA

# REINVENTING QUALITY

## 1995 Sourcebook of Innovative Programs for Quality Assurance & Quality Improvement of Community Services

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☐ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

**Report #45 • Published July 1995**

Research and Training Center on Residential Services and Community Living
College of Education and Human Development, University of Minnesota

The College of Education and Human Development

EC 305 774

BEST COPY AVAILABLE

# REINVENTING QUALITY

1995 Sourcebook of Innovative Programs for
Quality Assurance & Quality Improvement
of Community Services

**Compiled by**
**Ellen M. Blake, Robert W. Prouty, & K. Charlie Lakin**

Research and Training Center on Residential Services and Community Living
College of Education and Human Development, University of Minnesota

The College of Education
and Human Development

Additional copies of this report may be obtained from the Publications Office, Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, (612) 624-4512.

This publication is available in alternative formats upon request. To request an alternative format, contact the Publications Office listed above.

Preparation of this sourcebook was supported by a grant from the Administration on Developmental Disabilities (90DD0180) with supplemental support from the Health Care Financing Administration and the Centers for Disease Control, all of the U.S. Department of Health and Human Services, and a cooperative agreement (H133B80048) from the National Institute on Disability and Rehabilitation Research. The contents of this report do not reflect an official position of any supporting agency.

The recommended citation for this report is: Blake, E.M., Prouty, R.W., & Lakin, K.C., (1995). *Reinventing Quality* (1995 ed.). Minneapolis: University of Minnesota, Center on Residential Services and Community Living, Institute on Community Integration (UAP).

The University of Minnesota is committed to the policy that all persons shall have equal access to its programs, facilities, and employment without regard to race, color, creed, religion, national origin, sex, age, marital status, disability, public assistance status, veteran status, or sexual orientation.

Contains a minimum 10% postconsumer waste.

# TABLE OF CONTENTS


**PREFACE** ..... iv

**ACKNOWLEDGEMENTS** ..... vii

**OVERVIEW** ..... viii

**Innovative Practices** ..... I

**Statewide Information and Evaluation Systems** ..... I-1
- QUEST Survey and Certification Process ..... I-2
- Resident Outcome Licensure Surveys ..... I-3
- Quality Assurance in Colorado ..... I-4
- Quality Monitoring in Vermont ..... I-5
- Colorado Progress Assessment Review (COPAR) ..... I-6
- Quality Assurance and Information Systems ..... I-7
- Developmental Disabilities Quality Assurance Research Project ..... I-8
- COMPASS ..... I-9
- Standards Review Process of Community Living ..... I-10
- Utah's Approach to Quality Enhancement ..... I-11
- South Carolina State Health and Human Services Finance Commission ..... I-12
- California Consumer Outcomes ..... I-13

**Service Agency Development** ..... II-1
- National Management Mentoring Project ..... II-2
- Quality Team Approach ..... II-3
- Rings of Operation Structure ..... II-4
- Performance-Based Contracting Project ..... II-5
- Homeward Bound CQI ..... II-6
- Service Enhancement ..... II-7
- Oregon System of Continuous Quality Improvement ..... II-8
- Person-Centered System Design Project ..... II-9

**Systemwide Quality Enhancement** ..... III-1
- Continuous Quality Improvement in New Hampshire ..... III-2
- Consumer Empowerment Project ..... III-3
- Certification Project: Agencies Working Together In Partnership ..... III-4
- HCBS Waiver Quality Assurance ..... III-5
- Standards for Providers of Services ..... III-6
- New York State Commission on Quality of Care for the Mentally Disabled ..... III-7
- Strategic Plan for Revitalization of Mental Retardation Services in Philadelphia ..... III-8
- Wyoming Quality Review Project ..... III-9
- The Vermont Crisis Intervention Network ..... III-10

**Values Infusion** ..... IV-1
- It's About Lifestyle Choices ..... IV-2
- Alaska Service Principles ..... IV-3
- Tennessee Vision 2000 ..... IV-4

**Consumer and Citizen Monitoring** ..... V-1
Quality Measurement Instrument Review ..... V-2
Quality Assurance for People Moving ..... V-3
Oklahoma Advocates Involved in Monitoring (OK AIM) ..... V-4
Team Advocacy Project ..... V-5
Care Review Committees ..... V-6
Eastern Shores Community Monitoring ..... V-7
Quality Review Teams ..... V-8

**Community Relationship Building** ..... VI-1
Neighborhood Support Project ..... VI-2
Community Advocate Program ..... VI-3

**Technical Assistance** ..... VII-1
Life Quilters Project ..... VII-2
Reaching Up ..... VII-3
Developmental Disabilities Training Institute ..... VII-4

**Personnel Training and Professional Development** ..... VIII-1
North Dakota Statewide Developmental Disabilities Staff Training Program ..... VIII-2
Kennedy Fellows Mentoring Program ..... VIII-3
Universal Enhancement ..... VIII-4
Kansans Educating and Empowering Persons with Developmental Disabilities ..... VIII-5
Program Status Review ..... VIII-6
Leisure is for Everyone (Life Training) ..... VIII-7
Story Writing ..... VIII-8
Peer Review for Qualified Mental Retardation Professionals ..... VIII-9
Integrated Training ..... VIII-10
Minnesota Statewide Direct Service Training Initiative ..... VIII-11
Scout ..... VIII-12

**Advocacy Training and Support for Individuals and Families** ..... IX-1
Partnership Fund ..... IX-2
Parent Case Management ..... IX-3
Partners in Policymaking ..... IX-4
Community Resource Teams ..... IX-5
Pueblo Developmental Disabilities/Mental Health Consortium ..... IX-6
Neighborhood Living Project ..... IX-7
Atlanta Alliance on Developmental Disabilities Family Support Services ..... IX-8
Family Support Advisory Councils ..... IX-9
Community Capital Housing Project ..... IX-10
Residential Development ..... IX-11
"Parents are Experts" Parents Training Parents ..... IX-12
New Hampshire Self Determination Project ..... IX-13
Project PILOT (People Integrating and Learning Outdoors Together) ..... IX-14

**Best Practices** ..... X-1
Best Practices Forums ..... X-2
Nekton Best Practices Manual ..... X-3
Pennsylvania Search for Quality Practices in Early Intervention ..... X-4

**Quality Assurance in Community Supported Living Arrangements Programs (CSLA)** ..... XI-1
Quality Assurance in CSLA Programs ..... XI-2
Quality Assurance for CSLA-California ..... XI-3
Quality Assurance for CSLA-Maryland ..... XI-4
Quality Assurance for CSLA-Michigan ..... XI-5
Quality Assurance for CSLA-Rhode Island ..... XI-6
Quality Assurance for CSLA-Wisconsin ..... XI-7
Quality Assurance for CSLA-Florida ..... XI-8
Quality Assurance for CSLA-Illinois ..... XI-8
Quality Assurance for CSLA-Colorado ..... XI-10

**Networking** ..... XII-1
Positive Approach Committee ..... XII-2
Family Support Network ..... XII-3

**Accreditation** ..... XIII-1
Outcome-Based Performance Measures ..... XIII-2
CARF Accreditation ..... XIII-3

**APPENDIX A** ..... A-1

**INDEX BY STATE** ..... INDEX-1

# PREFACE

## History

In December 1992 a national conference to examine selected efforts by states to ensure and enhance the quality of services provided to persons with developmental disabilities was held in Alexandria, Virginia. The conference was co-sponsored by the National Association of State Directors of Developmental Disabilities Services and the Research and Training Center (RTC) on Residential Services and Community Living, Institute on Community Integration (UAP), University of Minnesota.

A sourcebook, *Reinventing Quality*, containing brief descriptions of innovative quality enhancement efforts by conference presenters and others was prepared for the 1992 Alexandria conference by the Research and Training Center. A revised and expanded version of the sourcebook was published by the RTC in June 1993. In February 1994 a third version of *Reinventing Quality* was published to coincide with a national conference, held in Hollywood, Florida and co-sponsored by the American Network of Community Options and Resources (ANCOR) and the RTC, on cooperative efforts by states and private service providers to improve service quality for persons with developmental disabilities. Six months later a fourth edition the RTC published a fourth edition.

## This Version

This fifth version of *Reinventing Quality* revises and expands previous descriptions of activities to assure and enhance the quality of services to persons with developmental disabilities. It was published shortly after a national conference, again co-sponsored by ANCOR and the Research and Training Center, titled "Redefining and Redesigning for Quality." This conference was held March 1995 in Phoenix, AR.

## Background

Recent years have seen a shift in long-term care for persons with developmental disabilities from large institutions to community settings. But people receiving community services can fully realize the potential for improved quality of life afforded by this movement only if quality assurance expectations and activities are changed significantly from those originally developed for institutional care.

While the nature of efforts to improve the quality of community services varies among and within states, recent years have brought many demonstrations of innovative and comprehensive quality assessment and enhancement practices. This sourcebook has been developed with the assumption that knowledge of and contact with such efforts may help others to fashion their own responses that not only protect the basic safety and well-being of individuals, but also encourage and support their preferred choices, personal growth, and individual lifestyles.

It is anticipated that this sourcebook will continue to be published periodically. You are invited to nominate innovative and exemplary quality related efforts for possible inclusion in subsequent versions. To do so write to the Editor, *Reinventing Quality*, RTC, University of Minnesota, 214 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455 or phone (612) 624-8246.

## Method

In compiling the first sourcebook, the Research and Training Center invited state directors of developmental disabilities services, executive directors of state developmental disabilities councils, managing attorneys of state protection and advocacy agencies, and a number of others with special knowledge and interests to identify innovative and exemplary programs that were designed to improve the quality of services to persons with developmental disabilities. A number of programs were identified.

Following on those referrals, key informants in each program were identified and interviewed by Center staff who then drafted a brief summary of each program selected for inclusion. The sourcebook does not include descriptions of "exemplary services" per se. Activities described are those seen as: a) systematic efforts to improve the quality of services to persons with developmental disabilities; b) containing elements that may be replicable elsewhere; c) likely to be of broad interest; and d) not redundant of other programs described. After review by key informant(s) for each program the summary descriptions were included in the publication. Efforts to identify programs for each new version have involved contacts with an increasing number of sources (e.g., service providers; advocacy organizations, other readers of previous versions). Programs included in previous versions are updated and included in the following versions.

## Content and Organization

Programs profiled in this sourcebook include a variety of efforts to support the redefinition, assessment and/or enhancement of quality in community services. Direct service programs, however, are not included. The programs and activities described have been subsumed under broad categories including:

1) statewide information and evaluation systems;
2) service agency development;
3) system-wide quality enhancement;
4) values infusion;
5) consumer and citizen monitoring;
6) community relationship building;
7) technical assistance;
8) personnel training and professional development;
9) advocacy training, and support for individuals and families;
10) best practices;
11) quality assurance in Medicaid Community Supported Living Arrangements programs; and
12) networking.

# ACKNOWLEDGEMENTS


### Information about Programs

The writers wish to thank the state directors of developmental disabilities services, the managing attorneys of protection and advocacy agencies, the executive directors of state developmental disabilities planning councils, ANCOR members, NASDDD members, and all others who submitted suggestions of programs for inclusion in the sourcebook. Thanks also go to the contact persons listed for each program profiled in the sourcebook. They provided the RTC with valuable information and updates on their quality enhancement initiatives. Thanks also to Gary Smith, Editor of the *Community Reporter*, for allowing the authors to base many of the profiles in this book on his articles in the *Community Reporter*.

### Editing and Preparation

Without the aid of Laura Lafrenz and Vicki Gaylord from the Institute on Community Integration the authors could not have published this sourcebook. The writers appreciate their help in editing, word processing, layout, and providing suggestions. Thanks also to Sylvia Rosen and Maret Freeman for their critical review.

# OVERVIEW

## Quality Assurance

# Searching for Quality in the Crooked Map Zone

By: John O'Brien*
Responsive Systems Associates
58 Willowwick Drive
Lithonia, GA 30038
Phone (404) 987-9785/Fax (206) 753-2768

---

Andrew Power, Chair of People First in the Australian Capitol Territory, explained the behavior of service managers who speak of choice and integration while they expand group homes and day activity centers –professionally controlled, segregated services. He said (personal communication, August 1993),

> Things have changed, but the managers and the staff haven't caught up yet. Now they are looking at a map that has gotten all stretched and crooked. When you drive with a crooked map, you get lost. The faster you drive on a crooked map, the faster you get lost.

Reflection on Power's insight suggests at least two ways that our maps can become detached from the territory we navigate in search of better quality services:

- *Our mental models can poorly represent the experiences and aspirations of people with disabilities and their families.* This happens when we ignore the effects of a long history of low expectations and segregation on a person's decisions, and declare, without considering what kind of assistance or further experiences might make a positive difference, "Supported living is not for her; she chooses to stay in the group home with her friends."

- *Our talk about quality improvement can be disconnected from the everyday constraints of service provision.* For example, we sometimes talk about people with disabilities as if they were customers. This happy mistake feeds the illusion that people's choice of a service warrant its quality, because customers could discipline ineffective services by simply taking their business elsewhere. We say this despite the market imperfections that arise from almost total control of expenditures by the agents of over committed bureaucracies, and from waiting lists for places in the only available services. We pretend that people could choose which mall to shop when they are, in fact, in hock to the company store.

As an introduction to a sourcebook on dozens of efforts to improve the quality of services, it cautions those who care about services for people with developmental disabilities to practice their map making skills by reporting the outlines of what they can see from their corner of the crooked map zone. As an aid to this rough and ready cartography, it presents a simple image of change with some thoughts on how we lose our orientation. This image guides two preliminary exercises in making such maps, one through day services, the other through improving our system's ways

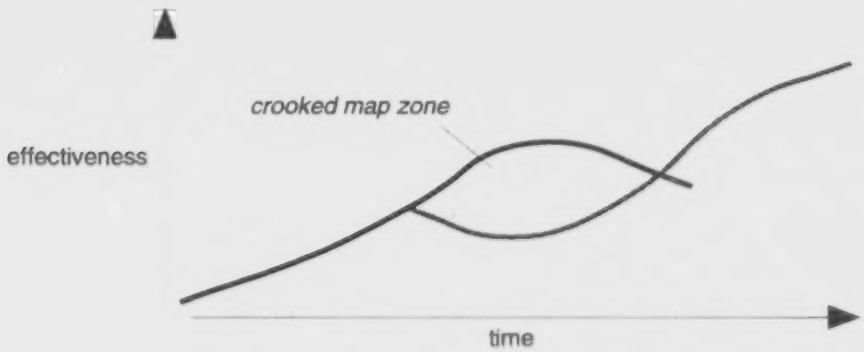
---

*Preparation of this paper was partially supported through a subcontract to Responsive Systems Associates from the Center on Human Policy, Syracuse University and Research and the Training Center on Community Living, University of Minnesota. The Research and Training Center on Community Living is supported through a cooperative agreement (H133B80048) with the National Institute on Disability & Rehabilitation Research, U.S. Department of Education.

to improve quality. Three reflections on these sketches –on emotion, on thoughtfully interpreting the lessons of quality improvement, and on the importance of design– suggest some likely places to carry on the search for quality in the crooked map zone.

**Losing our orientation**

To make our crooked map a bit straighter, or at least to notice when we start to get lost, we could try to better understand what stretches and twists it.




Charles Handy (1994) offers a helpful image for understanding the general structure of our situation. Visualize interlocking "S" curves, each tracing the life of a way of working (like those above). In this evolutionary metaphor, activities, ways of working, and models of the work and it's environment (maps) have a life cycle. Learning how to work better increases effectiveness incrementally, there is a reasonable fit between the work and its changing environment (the map fits). Over time, the work environment changes as new technologies create new possibilities, negative effects of past efforts accumulate, and preferences change (the map gets increasingly crooked). Effectiveness peaks and then begins to diminish rapidly; the faster we drive, the more lost we get.

The image of the interlocking S's suggests that an organization's stakeholders must enact a paradox in order to give their organization a chance to stay relevant. While one way of working still has potential for improvement, the organization begins to invest in a different way of working, which it bets will better fit the possibilities and problems emerging in the environment it is helping, in small ways, to shape. Waiting too long to make this shift –that is, waiting until after effectiveness has peaked– means trying to learn a new way while living with the rapidly accumulating problems of a failing way of working. Think of the dilemmas and incredible costs of pulling ourselves out of institutions that lost their rationale nearly a generation ago. But investing in learning a new way means accepting both the organizational costs of pursuing incompatible ways of working and the costs of trying new things. So, along the new way, effectiveness will most likely decrease before it increases. This will seem ill advised too many people, who will say, "It ain't broke, don't fix it." If their advice to stick with a winner is ignored, they will greet struggles with new problems by sympathetically observing, "Told you so."

Because most people with disabilities and their families have few if any alternatives to the existing services in their town, they directly bear the increasing costs of ineffectiveness, while service providers can maintain relative immunity. Unlike hula-hoop manufacturers, service operators do

not face the prospect of going out of business due to overlooking new opportunities to serve the people who rely on them. Indeed, they can happily listen to total quality training tapes while driving company cars to dedication ceremonies for obsolete new facilities. When fundamental change comes to today's human service organizations, it will come because innovators choose to listen carefully to less demanding signals than the messages generated by people with disabilities taking their business elsewhere[*]. It will come when innovators learn to listen carefully to the hopes and aspirations of the people who rely on them, not primarily because it is good business, but because it is right.

People need foresight, good judgment, and courage to decide when to begin investing in different ways of working and what new ways to develop. The more different a new way of working is from the old way, the harder it will be to make these judgments, and the harder it will be to persuade other stakeholders to join in the change. Two factors bedevil these judgments:

- *Innovators are discovering new ways of working at a rapid pace, so the period of the curves grows shorter.* As Donald Schön (1972) observes, the life of many important problems has become shorter than the time it takes to implement the solutions we conceive for them. Instead of building investments into structures with thirty year mortgages or expectations of life time career stability, we need to invest for much greater liquidity.

- *Boundaries around work environments have weakened, greatly increasing unpredictability and decreasing the confidence that we can steer our own course.* More than one innovator in residential services has been unpleasantly surprised by the amount of management attention claimed by occupational health and safety regulations and labor laws. And more and more discussions about the future of services for people with disabilities turn on participants' predictions about the future of the world economy.

Maps become more crooked (less reliable) as new ways of working develop alongside established ways of working. The more difference in assumptions, relationships, and methods there is between ways of working, the harder it will be for people traveling on one curve to understand those who are traveling on the other. What is more, travelers on both paths are likely to be people of good will, whose fates are closely linked, who use the same words to express increasingly different experiences. These difficulties in understanding will fragment a previously united field, at least for a time.

If we follow Bateson's (1972) definition of information as "a difference that makes a difference," the amount of information generated in the crooked map zone increases rapidly. When this information overwhelms our capacity to pattern it, we are disoriented and irritated by chaotic noise and we look for ways to damp it. We build privacy fences, "They are wrong and crazy, don't listen to them." We try to soak up difference, "We are doing the same thing as they are; there is no real difference between us." We bury our heads in routine, "We are too busy doing our work to take the time to listen to all that." We redirect attention to less chaotic topics. "Let's talk about paradigm shifts as if they were fashion decisions –we'll take the Swatch as our example of a paradigm shift." Deploying these simplifying tactics in a reasonable attempt to avoid the anxiety

---

[*]Some people argue eloquently for fundamental change and call for the creation of a freer market in services by providing people and their families with cash and the responsibility to purchase the services they want. This line of argument has much to commend it, and should be tried, and yet the current distribution of money and power seems likely to continue in enough places and for long enough to make the rest of this discussion worthwhile.

and irritation of too much information (too much difference), compounds the crookedness of our maps.

**Map making as a basic skill in quality improvement**

Finding our way through the crooked map zone calls for us to develop our skill as map makers. These will be rough sketches, more like the initial log of a new terrain than like the maps that come from the automobile club with the fastest routes traced and the speed traps flagged. Because disability is a civic issue, involving many stakeholders, we need to create public readings of maps through our changing services. Unless we can focus involved people on sharing their different perspectives and making and revising a common picture of the systems we want to improve, efforts at improvement will be shots in the dark.
The more accurately our maps reflect our current reality, the more complex and overwritten they will be, and the more frequently we must redraw them. Much of this complexity simply reflects the different interests and perspectives of:

- the people with disabilities, families, and staff who experience a system whose environment and fundamental technologies are changing in uncertain ways, and

- the neighbors, classmates, coworkers, and politicians who, for the most part, live at some distance from people with disabilities and regard them as strangers, well cared for by patient professionals.

Designers of quality improvement programs who do not consider the messiness, uncertainty, variety, conflict, and stress that characterize the terrain of service delivery will encourage people to look at a map that is fundamentally misleading because its looks neat and complete.

People who want to change the opportunities available to people with disabilities will judge such neat and complete maps as largely irrelevant to their work. They will pay polite attention until they can leave the planning meeting and return to their daily mess, unfortunately minus the learning that could come from thoughtful discussion. People who want to avoid change will use these maps' imaginary clarity as an invitation to take a vacation from the challenges of increasing the day to day opportunities for people with disabilities. This vacation can be a busy one, filled to the point of exhaustion with customer surveys, focus groups, quality circles, and nifty exercises in listening and problem solving. But unless these potentially useful tools help people work together to change relationships, boundaries, tasks, and ways of understanding, they are only diversions.

Making better maps can take some courage, because their patterns include ourselves and often conflicting judgments about the effects of our own actions. It requires acknowledgment of conflicting interests and understandings. It shapes a demand for learning new ways to do new things. It calls for recognition of a growing and often painful gap between our vision of what is possible and the reality of our own current practice.

**Reading the map through day services**

Consider a rough and ready history of day services in the United States through the image of the interlocking S curves. For more than thirty years, providers have worked to learn their place in a continuum of services that classifies every "client" according to disability related needs, and provides a service that matches the needs common to that class of disability. Based on this image and logic, we have built buildings, adopted assessment methods, defined entry and exit criteria, written curricula, delineated staff roles and career structures, negotiated methods of fiscal

and programmatic accountability, formed associations, and built a constituency among people with disabilities and their families, employers, and politicians. Based on this stable understanding of whom people with disabilities are and what they need, day services grew steadily more effective. Needs poorly met within existing classifications led to the elaboration of new classifications and corresponding new programs. For example, distinct day programs opened, often in the back rooms of existing facilities, for people who exhibited great difficulty in complying with the expectations about routines, roles, and relationships that were embodied in the typical program for people with their class of need. And, entrepreneurial managers applied new classifications in order to tap different sources of funding and thus expand the capacity of day services, as in some state's creation of "medical day care."

About twenty years ago, awareness of new problems and possibilities began to grow. Careful observers noticed the collision between fact and optimistic assumptions about people flowing through a continuum of day services toward independence. A few people with substantial disabilities got well-publicized opportunities to demonstrate their ability to do work that was far beyond the capacity assumed by existing program types (e.g., Gold, 1976; and summarized in Bellamy, 1979; Gold, 1980; Wehman, 1981). Some innovators began to shift their efforts into new ways of employing people. As they began to actively test assumptions about employability and discovered that many ordinary workplaces welcomed the contributions of significantly disabled people, supported employment took form. Most providers continued realizing the still increasing benefits of business as usual.

About ten years ago, advocates of supported employment captured an important share of policy attention in the US Office of Special Education and Rehabilitation Services (Will, 1984). This initiative signaled the states to move resources from improving congregate day services to learning to provide supported employment services. This shift has occurred, but as a whole the reinvestment curve has not been particularly steep. A decade after the call for system change, the share of attention given supported employment in meetings and plans remain disproportionate to its share of day services resources. By 1992, only about 18% of people in developmental disabilities day services were engaged in supported employment, although, encouragingly, the state of Vermont reported that almost 85% of people in day services receive supported employment services. (Braddock, 1994).

Recently, leaders in the supported employment field have begun vigorous debates in order to accelerate the movement of resources from congregate day services to supported employment (Mank, 1994; Wehman & Kregel, 1995). Based on the success of people with substantial disabilities and their coworkers and employers, they reassert that supported employment is for people with substantial disabilities, not just for those people who look ready from the perspective of the old way of working. The effects of these efforts, and the growing trend toward supported employment for those entering the adult service system for the first time, will further shift the demand environment for both supported employment and congregate day services. This will further increase differences between ways of working, and further distort our map.

For those providing supported employment services, the experience curve has not been nearly as smooth over the past ten years as the interlocking S's diagram suggests. The supported employment field grows more and more differentiated as some agencies shift their ways of providing supported employment, refocusing, sometimes repeatedly, from one curve to the next (O'Bryan & O'Brien, 1995; Wehman & Kregel, 1995). A growing number of providers are shifting their ways of working:

- *from* a concept of supported employment that included work crews, small businesses, enclaves, and individual employment *to* a singular focus on individual jobs.

- *from* primary emphasis on entry level jobs *to* a concern with career development.

- *from* job development strategies aimed at finding jobs and then selecting people with disabilities to fill them *to* individualized job development strategies, which begin with a profile of each person's interests, capacities, and preferences.

- *from* service staff as primary providers of training and supervision *to* service staff as organizers and consultants to employers, supervisors, and coworkers.

... *from* measuring success by comparing the wages of participants in supported employment with the wages of people in congregate day services *to* comparing the benefits of supported employment to the outcomes typical workers enjoy in terms of earnings, benefits, opportunities for personal improvement, working conditions, and job related social opportunities.

Not only does our initial image of neatly interlocking S's"overstates the smoothness of the path, it also understates the discontinuities between the two curves. Judgments are difficult enough when they concern the timing of major variations on existing technologies, tasks, and processes –such as Canon's development of a disposable copier cartridge (Nonaka, 1991). But the shift from congregate day services to supported employment involves much more fundamental change than that –it is at least as big a change as if Canon decided to go into the manufacture of aircraft. It means:

**1) accepting a new primary task and, thus, detaching from the familiar buildings, curricula, schedules, programs, and task assignments that grew up around the old primary task**

| established primary task | new primary task |
|---|---|
| training and otherwise readying people whose success in employment ultimately depends on themselves (i.e., their level of skill and motivation) and forces outside our responsibility (e.g., local patterns of discrimination) | being responsible to support people in employment |

**2) adopting new kinds of relationships with people who rely on services**

| established pattern of relationships | new pattern of relationships |
|---|---|
| classifying people into groups and dealing with performance problems through re-diagnosis and re-assignment of the person | understanding people's requirements for accommodation and assistance in the context of their changing job interests and opportunities; shared responsibility for performance problems |

**3) re-drawing the space and time boundaries of work**

| established boundaries | new boundaries |
|---|---|
| clients come to you and follow your schedule | joining in, and positively influencing, the rhythms and routines of different work places and different family and residential support situations |

**4) re-imagining the logic and the image of service work**

| established logic and image | new logic and image |
|---|---|
| matching services to groups formed by abstracting disability descriptors from clients' life experience | centering service and planning on particular, changing people in specific, changing work situations |
| understanding service as if it were work on an assembly line | understanding service as if it were organizing change in complex human systems |

While these changes call for vigorous practical action, they also have subtle aspects. For example, the image of the assembly line has great power to organize our activities. Even while we trashed the concept of a service continuum on the T-shirts we bought at conferences ("Pre- means never!"), we could be busily reconstructing the same pattern under different headings. Steven Taylor (1988) revealed this pitfall when he observed our tendency to match people to different forms of supported employment in a way that looked like matching people with greater apparent disability to services like work crews and enclaves and then matching people with less apparent disability to individualized supported employment. Even in reformed services, people with greater apparent disability still ended up in services that grouped and separated them, though in smaller groups, and sometimes on the premises of community businesses. His observation that we were erecting a "new continuum" won somewhat more irritated denial than thoughtful consideration among supported employment advocates. The years since Taylor's observation have seen practice divide along this dimension. Some programs focus on individual supported employment for all. Others entrench the assembly line idea by offering supported employment as one of a comprehensive array of rehabilitation services, bolted on to the side of existing day activity and sheltered work facilities.

**Reading a map through quality improvement**

Consider a rough and ready history of efforts to improve service quality through the image of the interlocking S curves. The dominant curve for the last thirty years has been plotted by two complimentary policies:

- Assure the presence of a sufficient number of staff members in adequate facilities. These staff members are trained in a variety of clinical disciplines and work in multidisciplinary teams to classify people with disabilities into appropriate groups, and then to assess, prescribe, implement, and revise individual programs for members of those groups.

- Based on expert opinion, judicial judgment, and political compromise, define standards by specifying procedures, facility characteristics, and staffing ratios; inspect to assure

documentation consistent with procedures and compliance with facility and staffing requirements; and, enforce correction of deficiencies through threat of sanctions including loss of funds or loss of operating license.

These policies have reinforced each other. Documented implementation of procedural, facility, and staffing standards is a condition of funding and sometimes a condition of compliance with court decrees. And detected deficiencies have driven the allocation of funds, especially when tied to the enforcement of federal court decrees and the maintenance of federal financial participation through the ICF-MR program. In some states, this reciprocal influence has been strong enough to direct a hugely disproportionate share of available funds to institutional facilities, and too meticulously regulated services for the people who have survived them; these systems have been surprised by a ballooning waiting list of people who grew up outside surveillance in their family homes.

For at least ten years, these standards led program implementation through a time of growing public investment. Most people interested in progress were lobbying for funds, drafting consent decrees, designing programs and policies, and training staff to catch up to the image of service so effectively communicated by the standards.

By the mid-1980's, the limitations of the established process became more clear. The problems seemed less with the content of the standards than with the sense that somehow the intent of the standards was getting lost in the way states applied them. Criticisms often included these observations: standards increasingly lagged ideas about good practice and contributed to inflexibility in implementing new approaches, they were dragging systems toward a least common denominator rather than pulling them toward higher aspirations; most people found enforcement procedures punitive and unhelpful, while at the same time facilities with widely perceived quality problems continued to operate unscathed; compliance and correction efforts promoted attention to paperwork and organizational activities over practical improvements and accomplishments; and there was far too little investment in improving program capacity to meet the intent behind standards.

In this context, two ideas began to gain currency:

- *Balancing the common focus on enforcement with methods for service enhancement (e.g., Bradley, et al., 1984, and summarized in Bradley, 1990).* This emphasis drew on the growing interest in quality improvement in industry, and it opened channels for exporting many ideas about industrial quality improvement into services for people with developmental disabilities.

- *Focusing attention on outcomes for people with developmental disabilities rather than on compliance with detailed specifications of service process (e.g., Bellamy, et al., 1984; Conroy & Feinstein, 1990; O'Brien, Poole, & Galloway, 1981).* An outcome focus was congenial to many people trained in applied behavioral analysis, and it promised greater flexibility and encouragement for emerging efforts in employment services, family support, and residential services.

While logically independent, these two ideas have become strongly associated in many efforts to reform quality improvement. Probably their clearest integration is embodied in the methods and standards of The Accreditation Council on Services for People with Disabilities (1993; 1994). These approach produce a coherent approach to improving quality by blending an outcome focus with concern for enhancing organizational capacity, a strong interest in importing ideas and

methods from business, and a structure for involving organizations in a network to promote quality.

As the publication of five editions of *Reinventing Quality* (Blake, Prouty, & Lakin, 1995) since 1992 demonstrates, the past three years has seen a rapid increase in the number and variety of efforts to improve approaches to quality improvement. A reading of the brief accounts of innovations described in the current edition of this collection suggests that emerging approaches to quality improvement are developing around one or more of these themes:

- *Quality measures are developed consultatively, rather than being defined by state authorities acting alone.* State authorities increasingly refer to their relationship with service providers as a partnership. Accordingly, some initiatives have involved service providers in the definition of quality standards and methods, others add the participation of representatives of advocacy groups (family members, and sometimes people with developmental disabilities themselves).

- *The attention is shifting from a primary focus on judgments about conformity to process standards.* Innovations balance inspection for conformity by giving increasing weight to judgments about people's quality of life. Often these judgments are made by inspectors or monitors on the basis of brief observations and interviews, and lead to recommendations for change.

- *In some initiatives, there is a clear connection between efforts to improve quality measures and the statement of system visions, missions, and strategic directions.* These statements frequently focus attention on people with developmental disabilities' experience of choice, integration, and productivity. These system aspirations have been interpreted to demand new ways of measuring and improving the kinds of things that matter to people as expressed in the system's mission.

- *Some initiatives distinguish "health and safety" issues – that they see as requiring standard, authoritative enforcement– from "quality of life" issues – that they see as allowing service providers wider latitude and greater variety of approaches.* On this understanding, a minimal set of regulations confines itself primarily to matters of "health and safety".

- *Responsibility for identifying quality problems is more widely shared, rather than being the sole duty of inspectors.* Some initiatives include program self surveys, others organize volunteer groups of citizen monitors. In some places there are organized supports to include people with developmental disabilities as program quality assessors.

- *Inspectors and monitors focus less on paperwork and more on observations and interviews as a basis for their judgments.*

- *Surveys and interviews allow people receiving services, their parents, and staff who work closely with them to express opinions about the quality of people's lives and their satisfaction with the services people receive.* Some of these surveys allow comparisons over time, and Colorado's approach allows comparison between the answers of people with developmental disabilities and people without disabilities.

- *While some initiatives extend to all community services, most involve only a part of the service system.* They are either linked to new funding (HCB waiver services or CSLA services), or to people moving from institutions, or to pilot projects.

- *Some state authorities recognize a distinction between the kind of relationships and processes necessary for enforcement and those involved in service enhancement.* There are varying approaches to this distinction: for example, Connecticut separates compliance activities from voluntary enhancement activities, while Massachusetts reports their integration into a single process.

- *The concepts and techniques of quality improvement often inform the design and justification of these efforts.* While there are many different approaches to improving quality, Deming's is the only approach specifically mentioned.

- *Service providing agencies and other organizations have initiated their own quality improvement efforts.* These efforts are evident in at least three, sometimes overlapping, areas of activity...

  ...learning about continuous quality improvement techniques and implementing quality improvement teams.
  ...improving program management through management development and mentoring and through internal reorganization.
  ...adopting an approach to person centered planning.

- *Efforts to disseminate learning have different emphases.* The New York State Commission on Quality of Care publishes case studies of neglectful or abusive service providers in a series called "Could This Happen in Your Program?" The Oregon System of Continuous Quality Improvement publishes descriptions of "Best Practices."

- *The importance of the relationship between service coordination and quality improvement is highlighted.* This is especially the case in quality improvement efforts that view the person with a developmental disability as a customer.

On this map, the discontinuities between emerging approaches to quality and established methods look less clear than they do in the map through day services. There are deep contrasts between supported employment and previous day services. In comparison, changes in quality improvement efforts seem more cautious and tentative. No clearly differentiated alternatives have yet emerged, though there is some experimentation with new emphasis and new techniques, and there is much new vocabulary.

Of course it is much easier for a few people to set up a supported employment program and set a clear new course than it is to change pattern in a function that affects a whole system. For many stakeholders, licensing and regulation have come to represent a promise that people will be healthy, safe, and decently looked after. Some stakeholders associate regulation with assurance that public funds are being well spent. And many state managers see the regulatory process as a necessary lever for control.

Redesign of the quality improvement process would require careful examination of each of these assumptions and the consideration of alternative ways to understand and satisfy the interests underlying them. The context for such discussion needs to be a common picture of the whole system as it is developing. This process of development includes not only our vision for better services but also the emotional responses our organizations have to stress and change, our opportunity to find ways to bring important lessons from other fields, the challenge of fundamentally changing the design of our services, and the emergence of new images for our

work. All of these issues have to influence the redesign. Otherwise, quality improvement will be a tangential enthusiasm.

**The feel of the crooked map zone**

Shifts in the fundamental dimensions of work life deeply stress organizations, groups, and people. So our ability to navigate the crooked map zone depends on our recognizing ourselves as unavoidably part of the system we are changing, and to understand the many weird effects of organizational, group, and individual emotion on our work. Fear, anger, anxiety, and envy are as much a part of changing ways of working as rational planning, creative problem solving, skilled performance, and thoughtful negotiation.

When we can support one another to work effectively with these emotional reactions to stress, we can be energized by them. When we try to banish them entirely –as when we try to look at ourselves simply as "objective" clinicians, or "hard nosed" managers, or "no nonsense" advocates for rights– we will become preoccupied and entangled in emotion no matter how bland or busy the tone of our discussions (Obholzer & Zagier-Roberts, 1994). As the official doctrine of the US Marine Corps (1994) notes:

> Leaders must study fear, understand it, and be prepared to cope with it. Like fear, courage takes many forms, from a stoic courage born of reasoned calculation to a fierce courage born of heightened emotion... Strong leadership which earns the respect and trust of subordinates can limit the effects of fear. Leaders should develop unit cohesion and esprit and the self-confidence of individuals within the unit... (p. 15)

In order to help people develop the cohesion and esprit necessary to cope with fear, quality improvement efforts can make time and space for those involved in change to meet person to person; express and name their frustration, confusion, and uncertainties; offer one another practical help, challenge, and encouragement; deal with emotional pressures to create false enemies or counterfeit saviors; and make sense enough of things to allow movement. Self-confidence grows as people work together on the difficult problems of expanding the real opportunities available to people with disabilities. As the map through day services shows, this means fundamental change in the boundaries and the work of most established organizations. Unless quality improvement efforts reach past existing boundaries and beliefs, people will have limited chances to develop confidence.

Weak mangers pretend that fear is not part of improving quality. Nothing about their work confuses or daunts them, things are predictable; they never need to reach out for support, they already have the answers. They delegate quality improvement techniques to subordinates within narrow and well defended boundaries. They refuse to move beyond slogans to engage in the emotional work necessary to change themselves and their own role and relationships so that they can meet new demands and realize new possibilities. They will have little authority when important change generates fear. Because they cannot face the effects of fear, quality improvement efforts under their authority will be superficial and dominated by fads and exhortations. In their artificially steady hands, quality improvement efforts will be too tame to matter.

**Being good interpreters**

For at least three generations, engineers and manufacturers have struggled to formulate a body of theory and practice that will increase the reliability with which people and machines can design and

make things that will interest and satisfy customers[2]. The past ten years have seen these efforts move from backstage in the factory into the spotlight of public attention. First, general managers of manufacturing companies, and then managers of services like airlines, financial institutions, and merchandisers sought competitive advantage by focusing on quality and appealing to the image of quality. Then politicians and public administrators looked to the discipline of quality improvement for some of the tools to reinvent government and for some of the justifications to legitimate their agenda.

How does the discipline of quality improvement help us find our way in the crooked map zone? There is hard won knowledge in the effort to improve manufacturing, but if people with developmental disabilities are to benefit from it, we must work hard to be good interpreters of theories and techniques developed and tested in a different economic context and on types of work that differ from the core work of supporting people to expand their opportunities in community life.

If we make our plans for quality improvement by copying diagrams, algorithms, and slogans from business best sellers, our efforts at quality improvement will, at best, be entertaining distractions, beside the point of relevant change. We will miss opportunities to thoughtfully consider the lessons learned through improving the quality of goods and services produced in freer markets than the near mynopsony[3] that governs services for people with developmental disabilities. And we will miss opportunities to contribute to the discipline of quality improvement by inventing new ways to improve the real systems that influence the lives of people with disabilities and their communities.

Clearly, many human service system functions are similar to the work of manufacturing, and especially service, industries. Providing information on an organization's services, filling in forms and processing information, and dealing with billing are examples of important activities that, no doubt, can be significantly improved through processes that are similar whether the transactions relate to operating a catalog sales operation, or an ambulatory surgery center, or a case management service.

Some tasks of the established services that congregate and therapeutically control people fit the logic of routine service. Treating guests with fairness and courtesy and maintaining cleanliness and order might be systematically improved in similar ways whether one operates a hotel or a group

---

*There are, of course, other applied disciplines for understanding and creating quality, including sociotechnical design (Trist & Murray, 1993) and Christopher Alexander's (e.g., 1994) approach to design, architecture, and building. These disciplines have an important contribution to make to improving services to people with disabilities, but they are not in nearly such good currency as ideas related to continual quality improvement.

*A monopsony is a condition in which there is only one buyer for the product of a number of sellers. The frustrated service manager who interrupted a conference presentation by an expert in customer satisfaction caught this point, "You are from another planet. My customer isn't the person with a disability. My customer is the state." As fiscal crises deepen, even states that delegate purchasing to regionally based case managers exercise increasingly rigorous control over the agents who act as surrogate purchasers for people with disabilities - the current slogan misapplied to this form of rationing is "managed care." State experiments with vouchers and cash transfers, while important for other reasons, are so small relative to overall expenditures that they have little effect on the shape of the service market. Interestingly in the case of people with developmental disabilities, the state mynopsonist not only controls demand, and thus has great influence on price, but can also dictate the details of the production of services, both through the exercise of police power (licensing) and through programmatic regulations imposed as a condition of purchase.

home. Continual improvement in the accurate and efficient administration of prescribed treatments might follow the same procedures whether one manages a hospital or an ICF-MR.

But what about the case of supporting people to live successfully in their own homes? It seems an odd proposition to have the people whose help you need to make it through the day think that the way to improve quality is to learn to treat you as if you were a guest in your own home, or like the resident of a world class one bed treatment center. This is assuredly an improvement over being abused, or neglected, or controlled arbitrarily; but it is altogether a different matter than the possibilities that emerging supported living services demonstrate.
The task of interpretation grows more interesting when we consider how the discipline of quality improvement can contribute to our search in the crooked map zone. Especially when we explore that edge of the crooked map zone inscribed by emerging support services. Here the core work is assisting people with developmental disabilities to participate in community life as valued citizens. Consider what differences there are between this sort of work, and a broad class of important human activities that includes: designing and making things; moving things and people; processing forms; administering routine medical and surgical treatments; and creating moments of delight for diners, hotel guests, or passengers.

One obvious difference is that when we work on improving the quality of supported employment and supported living we are working with exploratory efforts; not with stable systems whose range of outcomes has settled into a predictable pattern. This difference will decrease with time, but at least three important differences will remain:

- *Many people with disabilities seem to come to life in new ways when service workers choose to develop and maintain relationships that communicate a clear sense of belief in the person's worth, a strong sense that the person can achieve things that matter, and an active willingness to work alongside the person.* Usually, this kind of relationship grows over time, as people experience ups and downs together. It is less about defining, following, and refining correct procedures, than it is about living out a shared history that builds confidence and trust.

- *The process of developing community support is the art of re-defining boundaries.* Banks, landlords, employers, teachers, and community associations have drawn boundaries that leave people with developmental disabilities on the outside. And the experience of being on the outside creates a mutual sense of unfamiliarity and ineptitude that makes the boundary stronger from either side. Artful service workers find ways to encourage the redrawing of boundaries, so that people inside community settings make room for the participation and contribution of people with disabilities, and people with disabilities make room in their lives for participation in community life and relationships. This work is in between, finding and shaping and repairing opportunities for connection and contribution. Its general outlines can be sketched, and maybe even reliably tracked, but the art finds expression in what can be made of the unpredictable details arising in each situation. At least at this point, it is much harder to imagine what the process of support would look like when it is "in statistical control" than it is to see the meaning of a control chart that plots the accuracy of inventory counts over time.

- *It's hard to define the product, customer, and the producer in stable terms.* The primary task of support services is to create many constellations of people with developmental disabilities, support workers, and community members who coproduce mutually valuable experiences. Think of a worker with a developmental disability, a coworker, and a job coach collaborating to refine a job to better accommodate the worker's disability and thus

> increase the worker's contribution. It is hard to decide who is the customer and who is the producer; it is more fruitful to see a constellation of people creating value for and with each other, both throughout the economic contribution their work makes and through the benefits of their relationships with one another (Normann & Ramírez, 1994).

There is some danger in minimizing these differences out of hand. Saying, as a quality improvement enthusiast did in keynoting a recent conference, "Quality is quality. Service is service. Why should we human service workers be so precious? Whether you're selling shoes to shoppers or selling people with disabilities to employers, the same tools will work to make improvements." The danger is that our efforts to improve quality might thoughtlessly encourage forms of service that treat people with disabilities as if they were objects to be shaped according to a blueprint, moved, stored, processed, and marketed; or as if they were patients, experiencing life as an endless series of routine treatments; or as if they were temporary guests, enjoying endless episodes of delightful service on a plane that they can never get off, and from which their cheerily impersonal attendants can only escape by quitting their jobs.

As an exercise in interpretation, we can look at an important issue in an emerging support service through the lens of an important idea from the discipline of quality improvement. The first results of such a look might horrify an experienced practitioner of quality improvement. "That is not it at all," she might say. So much the better, because the mistake will clarify understanding in terms of important work in support services, instead of keeping the concept in more abstract and analogous terms.

According to W. Edwards Deming (1993), knowledge about variation, its sources and its messages, is one of the four related parts of a system of profound knowledge necessary for improving quality. "Life is variation" he says, "Variation there will always be, between people, in output, in service, in product. What is the variation trying to tell us about a process, and about the people that work in it?" (p 101). He then goes on to make important distinctions between special causes and common causes of deviation and between stable (i.e., predictable) and unstable states in a system. These distinctions are based on the image of a control chart, an array of data that displays variation in discrete events over time.

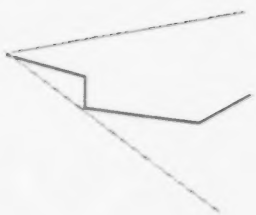
A group of people involved in the Oregon Supported Living Network gathered to help one of their members deal better with a significant quality problem: the turn over of live-in companions. While all of the stakeholders involved in the program are highly satisfied with it over all, each is concerned about turnover among these key people. The program is small, supporting 18 people in 16 households. Nevertheless, analysis revealed at least six apparently different sources of variation related to staff turnover.

Following are brief summaries of the four sources of variation that originate with the person with a developmental disability. The graphics are not attempts at control charts, they are simply a notional representation of the way the variation manifests over time. For example, in this program, people's capacity to direct and supervise their assistants was extremely low at first. But everyone has increased this capacity gradually, usually in a way that combines small changes with periods most people described as "bumpy": periods of relative stability followed by jumps that surprise both the person and the live-in assistant. Companions who match well with a person who has little to say about how they do their work often have considerable difficulty as people become more assertive. This is one of the reasons that several companions reported leaving.

**Individual capacity to direct**

- For most people, will increase gradually, with experiences that develop confidence and skill.
- For many people, will not increase enough to allow complete independence

Offer mentoring, training, & support



**Individual need for assistance**

- Difficult to predict
- Varies within relatively wide limits.
- Can shift suddenly (e.g. decrease, if a person becomes able to stay overnight without paid help, or increase if a person has an accident.

Maintain flexibility

**Individual preferences**

- Change occasionally as people experiment, or get bored and want a change.
- May require careful listening and observation or responses to changes.
- Expression is often much stronger in good relationships.

- Listen & observe
- Invite people to try new things.
- Adjust & check

**Individual sense of future**

- For some people, new ideas about a desirable future call for new kinds of basic support (e.g. marriage or deciding to live without overnight staff, or desiring to buy a house).
- May take time and negotiation with person, family, program funders.

Redesign

Note that each of these sources of variation is intended, positive results of the program, which also play an important part in increasing turnover. Increased independence in directing necessary help, matching amounts and kinds of support to changing need for assistance, supporting greater choice in daily activities, and encouraging a new sense of a desirable future are all reasons to provide a supported living program. In a sense, the intended result of supported living is greater variation, at least along these dimensions. A successful program will see difference increase, both for the same person over time and between the people the program serves. This supported living program is and wants to be a variety generator, a task that calls on them to continually increase personal and organizational flexibility and to increase the resiliency of their relationships.

In this case, discussion of the sources of variation led to a better understanding of the quality problem. Some turnover happens for reasons outside the relationship between the person with a developmental disability and the companion, but much of it happens because of the way the relationship develops as the person with a developmental disability changes in desired ways. This understanding led to a different plan for quality improvement, including the development of ways to support open negotiation in changing relationships, ways to strengthen continuity of important relationships as turnover happens, and ways to assist people who do not want the live-in companions at all.

So, while a control chart on the incidence of turn over is helpful, variation has even more to say in this situation. The concept of variation becomes more useful when practitioners invest attention in interpreting it from within the crooked map zone. There is every reason to think that the other foundations of quality improvement would be equally helpful as ways to make sense of the complex and changing situation of emerging services for people with developmental disabilities.

**The Problem of Design**

To increase understanding of one of his seminal papers, Jay Forrester (1976), asked his students, "If we wanted to make the greatest difference in the overall performance of a supertanker, whose performance would we focus on?" Answers included: the captain, the team of a ship's officers, the crew, and the cook. In response, Forrester argued that the naval architect who designed the ship established its most important limits and possibilities. He said that organizational design is the neglected discipline in the search for better quality. By analogy with the tanker, the greatest leverage for improved quality in any organization is not within a worker's performance or within manager's efforts to deal with the stream of daily problems, but in careful design and redesign of the organization itself. The paper he was teaching contends that common forms of business organization are fundamentally mismatched with the tasks required of them in a rapidly changing environment. Only a few organizations heard him.

Forrester's example of the supertanker resonates with Deming's (1993) repeated advocacy for a difficult idea. He said that the performance of a stable system cannot be materially improved by those working within the system. The performance of a stable system is the responsibility of those whose job it is to design and work on the system as a whole: it's management. That is why he believes that rewarding and punishing performers within the system, on the basis of different levels of performance is unfair, senseless, and wasteful. He noted ruefully that this is one of the most difficult ideas he tried to communicate to managers. Many managers seem more interested in abdicating responsibility for quality by blaming or praising workers, and delegating quality concerns to them, than they are in doing their own work by improving the design of the system as a whole.

Wolf Wolfensberger and Linda Glenn made a similar argument when they decided that *PASS 3* (1975), their instrument for measuring the extent to which a service follows the principle of normalization, would award the highest proportion of the possible score to the fit between the program's overall design and the most important needs of the people the program serves. This view of program design, called model coherency, looks at the harmony between the most important needs of the people who rely on a program and the interaction of five elements of the program: the overall model of service that the program embodies, the goals it pursues, the processes it adopts, the way it groups the people it serves, and the identity and competency of the workers who staff it.

Those of us who learned to see services through the lens of model coherency quickly faced a sobering lesson. Most programs were simply not designed in a way that was consistent with the goals they espoused. In those days, espoused goals commonly included maximizing individual potential, offering life conditions and experiences that were as close to normal as possible, and providing for social integration. In program after program, the issue was not poor performance of particular tasks that made sense in terms of these goals. The overriding issue was counterproductive design: groupings, settings, methods, and staff roles and relationships structured as if to achieve the opposite of the program's stated goals.

A second lesson followed the first. Most programs were not designed at all; they were assembled like the plastic model warplanes boys used to glue together. Funds arrived with all the specifications attached. The job of managers was not to collaborate with families and local community members to plan a program that expressed a sense of place; the job of managers was to assemble the pieces as quickly as possible, with as much local involvement in fund raising as possible, and get on with doing good. In those days, managers of day centers and group homes learned as much about program design as did the managers of the MacDonald's hamburger stands that popped up at about the same rate and in about the same way. A systemwide pattern of expecting someone else to do the thinking about program design was reinforced by wave after wave of train the trainers workshops aimed at teaching people "the model" solution to every problem. In such a climate, the only people who grow smarter and stronger at designing and redesigning services to better match a deepening understanding of the local situation of people with disabilities are those who do so at considerable personal effort, and with low doses of external reward.

A third lesson followed the second. Discussing the issue of program design in a helpful way was very difficult. Once they got the idea of model coherency, people found it easy to see basic design problems in programs other than their own, but facing the redesign of one's own program was daunting. Defensiveness was high, and angry rejection of the entire process for unarticulated reasons was common. Some new programs –including some early supported living and supported employment projects– were designed with model coherency in mind, but reconstructing programs from the foundation seemed too heavy a burden to lift.

Today's common goals of independence, productivity, and inclusion has refined our sense of direction. But today's established programs were built with the same templates, and the same disregard for the design task, as the programs that taught the difficult lesson of flawed design twenty years ago. Today, there is often greater regard for people's choices within program walls, activities and routines may be more engaging and less silly and childlike, and people may be better dressed and go on more outings. But typical programs still congregate, segregate, and control people by unconsidered design. Reform efforts are most likely to add on supported employment or supported living. Few reforms result in what some people aptly call conversion; that is, closing the activity center or the congregate residence and reinvesting fully in a program designed around the

possibilities of the people in a particular place. The usual methods of quality improvement continue to better the ways people are congregated, segregated, and controlled. This is worthy work as long as people with disabilities are congregated, segregated. and controlled, but it won't contribute much to fundamental change. It does not raise the basic question of program design, "Can you get there from here, or do you have to start somewhere else?"

One of today's challenges is getting over the habits of passivity that lead service managers to avoid working on redesigning the systems in which they hold authority. The most important work to be done involves collaborating with people with disabilities, family members, and community members to shape and sustain a growing variety of opportunities and supports. It would be nice if this work could be done in a climate of widespread appreciation for human services, and in a time of rapidly increasing budgets. But no matter how the wider environment may be, the importance of the work remains.

The highest leverage today is probably in the redesign of state service systems. In most states, enough positive things bubble up from the crooked map zone to clearly show the way that supports can and should develop. There are also enough large scale problems whose intractability could signal the defeat of the established way of organizing the system. A redesign process could outline the modest but important long term contribution the state level system can make to better lives for people with developmental disabilities. But there are big economic stakes in the established system, and powerful people whose careers are stable within it. Many constituents have good reasons to fear that change would as likely be for the worse as for the better, and many politicians feel that they were promised a ble solution to the developmental disabilities problem some years ago. Room enough for some good things to grow can be found in even the most rigid state system. And so the time may not be ripe for state level change.

All over the world, people with developmental disabilities, and their families, and a remarkable number of ordinary community members have joined service staff members who want to learn better ways to work. These constellations demonstrate unforeseen possibilities in the way real people are living and working and learning and recreating and otherwise contributing to civic life. Will they get lost in the crooked map zone, wandering in small bands, increasingly detached from the main body of service provision? Will their work lead the field out of the crooked map zone, and into a new period of common understanding and systematic improvement, based on a recognition of the importance of joining people with developmental disabilities to build more inclusive communities?

The answer to this cliff hanger lies in an episode of the serial that we have yet to write. Some people want to continue to go in two directions at once, stretching and distorting our common map still further. But Andrew Power has made up his mind about the future he wants to work for (personal communication, August 1993):

> We don't know where the service managers and the staff will be. But we know where we'll be. We'll be fighting for our rights. As many of us as can get the help we need will be working in real jobs in the community and living in real homes that we have the keys to. We'll help each other out with this as much as we can. We hope the system people will see the right way, and come along and help too.

**References**


The Accreditation Council on Services for People with Disabilities (1994). *The quality consortium.* Landover, MD: The Accreditation Council on Services for People with Disabilities.

The Accreditation Council on Services for People with Disabilities (1993). *Outcome based performance measures.* Landover, MD: The Accreditation Council on Services for People with Disabilities.

Alexander, C. (1994). *A foreshadowing of 21st century art: The color and geometry of very early Turkish carpets.* New York: Oxford University Press.

Bateson, G. (1972). *Steps to an ecology of mind.* New York: Ballantine Books.

Bellamy, G. T. (1979). *Vocational habilitation of severely retarded adults.* Baltimore, MD: University Park Press.

Bellamy, G.T., Rhodes, L., Wilcox, B., Albin, J., Mank, D., Boles, S., Horner, R., Collins, M., & Turner, J. (1984). Quality and equality in employment services for adults with severe disabilities. *Journal of the Association for Persons with Severe Handicaps, 9*(4), 270-277.

Blake, E., Prouty, R., & Lakin, C. (1995). *Reinventing quality (1995 edition).* Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Braddock, D. (1994). New frontiers in mental retardation. *Mental Retardation, 32,* 6, 441-442.

Bradley, V. (1990). Conceptual issues in quality assurance. In V. Bradley & H. Bersani, Eds. *Quality assurance for individuals with developmental disabilities: It's everybody's business.* (pp. 3-15). Baltimore, MD: Paul Brookes Publishing Co.

Bradley, V., Ashbaugh, J., Harder, P., Allard, M.A., Mulkern, V., & Stoddard, S. (1984). *Assessing and enhancing the quality of services: A guide for the human services field.* Cambridge, MA: Human Services Research Institute.

Conroy, J. & Feinstein, C. (1990). A new way of thinking about quality. In V. Bradley & H. Bersani, Eds. *Quality assurance for individuals with developmental disabilities: It's everybody's business.* (pp. 263-278). Baltimore, MD: Paul Brookes Publishing Co., pp. 263-278.

Deming, W.E. (1993). *The new economics for industry, government, education.* Cambridge, MA: MIT Center for Advanced Engineering Study.

Forrester, J.W. (1976). A new corporate design. In *The collected papers of Jay W. Forrester,* (pp.93-109). Cambridge, MA: Wright-Allen Press, pp. 93-109.

Gold, M. (1976). Task analysis of a complex assembly task by the retarded blind. *Exceptional Children, 43,* 78-84.

Gold, M. (1980). *Did I say that? Articles and commentary on the Try Another Way system.* Champaign, IL: Research Press Company.

Handy, C. (1994). *The empty raincoat: Making sense of the future.* London: Hutchinson.

Mank, D. (1994).The underachievement of supported employment: A call for reinvestment. *Journal of Disability Policy Studies, 5* (2), 1-24.

Nonaka, I. (1991, November-December). The knowledge creating company. *Harvard Business Review*, 96-104.

Normann, R. & Ramírez, R. (1994). *Designing interactive strategy: From value chain to value constellation.* Chichester, England: JohnWiley & Sons.

Obholzer, A. & Zagier-Roberts, V. (1994). The unconscious at work: Individual and organizational stress in the human services. London: Routledge.

O'Brien, J. (1995). *Living-in: Summary of a learning group visit to Albertina Kerr Centers.* Lithonia, GA: Responsive Systems Associates.

O'Brien, J., Poole, C., & Galloway, C. (1981). *Accomplishments in residential services.* Olympia, WA: Governors Council on Developmental Disabilities.

O'Bryan, A. & O'Brien, J. (1995). *SEQA: Supported employment quality assurance.* Manchester, England: National Development Team for Services to People with Learning Disabilities.

Schön, D. (1972). *Beyond the stable state.* New York: Norton.

Taylor, S. (1988). Caught in the continuum . *Journal of the Association for Persons with Severe Handicaps, 13*(1), 45-53.

Trist, E. & Murray, H. (1993). *The sociotechnical perspective. Volume II: The social engagement of social science, A Tavistock anthology*. Philadelphia, PA: The University of Pennsylvania Press.

US Marine Corps (1994). *Warfighting.* New York: Doubleday Currency.

Wehman, P. (1981). *Competitive employment: New horizons for severely disabled individuals*. Baltimore, MD: Paul Brookes Publishing.

Wehman, P. & Kregel, J. (1995). At the crossroads: Supported employment ten years later. Richmond, VA: VCU Research & Training Center.

Will, M. (1984). *Supported employment for adults with severe disabilities: An OSERS program initiative*. Washington, DC: US Department of Education.

Wolfensberger, W. & Glenn, L. (1975). *PASS 3*. Downsview, ON: National Institute on Mental Retardation.

# INNOVATIVE PRACTICES

## Statewide Information and Evaluation Systems

# QUEST Survey and Certification Process

*A unified licensing and evaluation process*

Area Served: Massachusetts

Contact: June Rowe, Director of Survey and Certification
Department of Mental Retardation
160 North Washington Street
Boston, MA 02114
Phone (617) 727-5608 EXT 236/Fax (617) 727-9868

---

The Massachusetts Department of Mental Retardation (DMR) integrated its licensing, quality assurance and human rights divisions to form the Office of Quality Enhancement (OQE). OQE has set up a new provider certification system: the Quality Enhancement Survey Tool (QUEST).

QUEST comprises six quality of life areas: rights and dignity, individual control, community membership, relationships, personal growth and accomplishments, and personal well-being. An additional seventh area defines outcome measures for the organization. Each area of QUEST addresses outcomes, measures, source, ratings, and comments.

In January 1994, certification based on QUEST began for all providers. The survey process examines the quality of life for a sample of individuals with disabilities. Teams of DMR Quality Enhancement Specialists, consumers, and family members conduct the surveys. Each team member makes an individual survey. The information accumulated from their individual reviews becomes the basis for certifying agencies. During feedback meetings, teams present providers with ratings, recommendations, and areas of improvement. Within fifteen days of the feedback meetings, written reports are completed and sent to providers, and DMR Regional and Area Directors. The products of the surveys are levels of certification ranging from noncertification to two-year certification for providers.

Now that the system has been functioning for a year, the QUEST tool and process are undergoing minor changes to enhance effectiveness and reliability. Like the current tool, input is being solicited from providers, DMR staff, and other interested citizens. These changes will be incorporated in April 1995.

QUEST is applicable to both residential and day services, including supported employment and semi-independent living situations. It was developed by persons with various affiliations and pilot-tested with 12 service providers. The Department has found QUEST to be not only effective in evaluating the quality-of-life of people with developmental disabilities, but also efficient in combining several functions into one process.

For more information contact June Rowe at (617) 727-5608, Ext. 236.

# Resident Outcome Licensure Surveys

*An outcome-based state licensing survey*

Area Served: Ohio

Contact: Charles Grunkemeyer, Chief
Office of Licensure
Ohio Department of Mental Retardation and
Developmental Disabilities
Columbus, OH 43266
Phone (614) 466-6670/Fax (614) 644-6676

---

The Ohio Department of Mental Retardation and Developmental Disabilities' (DMRDD) Office of Licensure uses a survey process which emphasizes observations and interviews. These surveys are called Resident Outcome Licensure Surveys.

Resident Outcome Licensure Surveys are unannounced. Usually they occur when consumers are home to monitor for licensure rule compliance, and investigate unusual incidents or complaints. Surveyors use several methods to assess compliance with Ohio's Rules of Licensure. They include: observations of the facilities; interaction between residents and staff; conversations with residents and staff; and record reviews. Surveyors focus on the following areas within the Rules of Licensure: staff training; conditions of the facilities; food and nutrition; clothing and personal effects; fire and safety requirements; drugs and medical procedures; and residents' finances, rights, and individual plans.

At the end of each visit, surveyors document a summary that highlights topics discussed, comments, and suggestions. Surveys conclude with exit interviews, during which the surveyors, staff, and residents have the opportunity to discuss and respond to specific concerns. If warranted, surveyors document citations, and issue them upon exiting.

For more information, or a copy of the Office of Licensure Handbook on Resident Outcome Licensure Surveys, contact Charles Grunkemeyer at (614) 466-6670.

# Quality Assurance in Colorado

*An outcome and assistive based method for state quality assurance*

Area Served: Colorado

Contact: Heidi Cunningham, Program Manager
Program Quality
Division for Developmental Disabilities
3824 West Princeton Circle
Denver, CO 80236
Phone (303) 762-4581/Fax (303) 762-4300

---

Quality Assurance in Colorado's Division for Developmental Disabilities is moving from rule compliance enforcement to working with providers. While the state will not relinquish its obligation to enforce compliance, it now shares that responsibility with providers and is developing a partnership with providers.

Colorado's State Central Office established the Quality Assurance Section in 1985. At that time Colorado had a system of group homes and segregated adult day programs. The state was just beginning to develop HCBS waiver, supported employment, family support, and non-congregate residential programs. The system now consists of highly individualized services, including supported living. These changes, in addition to the endorsement by Colorado's governor of outcome-based measures and total quality management, prompted a reassessment of regulatory compliance and service quality evaluations.

The staff of the Program Quality Section (PQS) looked at the relevance of the activities the PQS were performing. They assessed the effectiveness of those activities on helping providers to improve the quality of their services, or assisting consumers to affect the quality of their own lives. They also reviewed the work done in other states and talked with national experts in quality assurance and developmental disabilities.

PQS now examines each service entity and reviews factors such as, length of operation; results of the last regulatory survey; and size, location, and organizational sophistication. With this information PQS negotiates how they will work with providers to assure quality. Rather than state staff members conducting traditional surveys, they talk with providers about how they can work together to review compliance and quality enhancement issues.

For more information or materials contact Heidi Cunningham at (303) 762-4581.

# Quality Monitoring in Vermont

*Monitoring for quality-of-life issues and utilizing a longitudinal database tracking system*

Area Served: Vermont

Contact: Carol Leech, Senior Community Alternative Specialist
Vermont Department of Health and Mental Retardation
103 South Main Street
Waterbury, VT 05671-1601
Phone (802) 241-2614/Fax (802) 241-3052

---

The state of Vermont has developed *Guidelines for Quality Services* to ensure an effective evaluation process. This process incorporates input from people affected by the mental retardation system.

This monitoring and evaluation system identifies minimally acceptable types and levels of activity, while minimizing the quantity of documentation currently required of provider agencies. The evaluation and monitoring processes focus on issues concerning a person's health, safety, rights, and quality of life.

Vermont has created a list of person-centered goals and corresponding quality-of-life outcomes that are used in its monitoring process. To assess the quality of services within a provider agency, the DMR conducts reviews using the fore mentioned goals and outcomes annually for about fifty percent of persons who receive services. An example of one such goal is "People are treated with respect and dignity." An expected outcome related to this goal is "Environments and services allow for personal privacy."

Vermont has also developed a database to monitor the effectiveness of Vermont's quality efforts. The database will be able to track a single goal longitudinally for one consumer, a provider agency, or the entire state system.

For more information contact Carol Leech at (802) 241-2614.

# Colorado Progress Assessment Review (COPAR)

*Longitudinal evaluation of quality*

Area Served: Colorado

Contact: Judy Ruth, Section Chief
Data Management
Division for Developmental Disabilities
3824 West Princeton Circle
Denver, CO 80236
Phone (303) 762-4578/Fax (303) 762-4300

---

The Colorado Division for Developmental Disabilities' mission statement has established community inclusion, responsible choice, control, belonging, relationships, competencies, talent, security, and self-respect as values for services to citizens with developmental disabilities. To evaluate actual outcomes, in relation to the values in its mission statement, the state developed the Colorado Progress Assessment Review (COPAR), a longitudinal evaluation program. COPAR was begun in 1986 with a legislative mandate that the State Auditor's Office (SAO) perform an independent evaluation of the progress of individuals with developmental disabilities. From this mandate a Steering Committee, made up of various stakeholders, was formed to advise the SAO.

COPAR asks structured and unstructured questions directly of a sample of persons receiving services, or proxy respondents, and providers of services on a longitudinal basis to determine program and service outcomes, and differences across programs and regions. Questions are also asked pre- and post-participation in new service initiatives to ascertain whether they have improved the lives of the persons served.

The state contracts with a private research organization to collect data in the field and to gather and evaluate instruments that are used elsewhere to address similar issues. These data are used to improve Colorado's current list of questions in COPAR. Additionally, studies have been conducted that compare the decision making, satisfaction, and community inclusion of persons with and without developmental disabilities in the Colorado general population to develop standards of comparison for persons served by the division.

COPAR is managed by the Colorado Division for Developmental Disabilities. Funds are provided by state general appropriations ($41,000) and the Division for Developmental Disabilities (approximately $21,000).

COPAR reports and forms are available from Judy Ruth at (303) 762-4578.

# Quality Assurance and Information Systems

*A computerized statewide management information system*

Area Served: Minnesota

Contact: James Franczyk, Research, Evaluation and Planning Director
Division for Persons with Developmental Disabilities
Minnesota Department of Human Services
444 Lafayette Road
St. Paul, MN 55155
Phone (612) 296-2171/Fax (612) 297-4692

---

Developing, maintaining and improving service quality for persons with developmental disabilities requires a variety of technical support, such as ready access to information that is necessary for individual and system planning and review. The quality of information available often determines the quality of decisions made.

Minnesota has developed and continues to enhance a fully computerized statewide management information system. Its purpose is to gather, analyze, and report data in response to generic and idiosyncratic needs. The Division for Persons with Developmental Disabilities' (DPDD) management system draws on databases within and outside the Department of Human Services (DHS) to provide information. Examples of data available include individual information, such as service recipient characteristics; services, costs and systemic information, such as county-by-county cumulative data on service systems; waiting lists; expenditures; and summary client profiles.

DPDD staff and county agencies use both recurring reports and interactive access to obtain information for planning individual programs. Same-service cost comparisons across different geographic regions of the state and different service providers, for example, become possible with the collection, storage, and retrieval capacity of relevant data in place. Joint planning to focus limited specialized training, technical assistance, and direct service resources become feasible. Policy makers can assess, modify, and enrich policy initiatives on the basis of anecdotal evidence or theoretical positions by using objective analysis of systemwide data.

The ongoing review and expansion of existing databases try to insure continued relevancy of the DHS/DPDD management information system.

For more information contact James Franczyk at (612) 296-2171.

# Developmental Disabilities Quality Assurance Research Project

*A longitudinal assessment of consumer outcomes*

Area Served: Oklahoma

Contact: Ed Arquitt, Principal Investigator
Department of Sociology
Oklahoma State University
Stillwater, OK 74078-0395
Phone (405) 744-6104/Fax (405) 744-5780

---

Tapping the dimensions of quality of life and outcomes that are important to and valued by people with developmental disabilities is an important quality enhancement activity.

The Department of Human Services Developmental Disabilities Services Division contracts with Oklahoma State University's Department of Sociology to conduct annual independent assessments of consumer outcomes. Changes in independence, integration, productivity, and satisfaction are tracked longitudinally to measure quality-of-life enhancement. Assessments are completed annually on approximately 3,700 persons at various residential sites throughout Oklahoma. Residential sites include state schools, intermediate care facilities for persons with mental retardation, nursing homes, private homes, group homes, and foster homes, as well as supported, semi-independent and independent living arrangements. The assessment instrument used has three parts: an interview with the primary care-giver, a consumer satisfaction interview, and a qualitative site assessment.

Yearly reports of the survey research are made to the Oklahoma Quality Assurance Advisory Council. Represented on the council are primary consumers, family members, service providers, Department of Human Services staff, Oklahoma Developmental Disabilities Council, research staff and consultants. Survey reports are disseminated to provider agencies who use the results to improve service quality.

Research staff members have accrued considerable experience in the development of a computerized tracking system to follow previously institutionalized individuals who relocate to community settings. An unanticipated outcome of the study has been the adaptation of the consumer satisfaction portion to a picture book format that allows nonverbal consumers to participate.

For more information contact Barbara Murray or Amanda Fullerton, directors of the study's day-to-day activities, or Ed Arquitt at (405) 744-6104.

# COMPASS

*A quality assurance pilot project based on consumerism, outcomes, management planning and agency self-survey*

Area Served: New York State

Contact: Thomas J. Cuite, Deputy Commissioner
Quality Assurance
State of New York Office of Mental Retardation
and Developmental Disabilities
44 Holland Avenue
Albany, NY 12229
Phone (518) 474-3625/Fax (518) 486-1108

---

New York began a pilot project COMPASS in 1993 to study a new oversight mechanism. It is intended to effectively promote quality improvement and an innovative approach to agency management, planning, and delivery of services to individuals with developmental disabilities. COMPASS comprises four elements: Consumerism, Outcomes, Management Plan, and Agency Self-Survey. It emphasizes the enhancement of services focused on valued outcomes and corresponding adherence to regulations based on routine self-surveys. It maintains governmental oversight responsibility, but in a more positive outcome-oriented manner than that of assessing regulatory compliance. It permits oversight bodies to make decisions based on how an agency is managed and if the agency's outcomes are achieved, and not solely on the basis of regulatory deficiencies.

The COMPASS Pilot Project involved 24 agencies serving 11,246 consumers and was operational for 18 months. A subsequent evaluation found COMPASS to be quite successful in the following areas: (1) the majority of agencies maintained an unacceptable level of regulatory compliance during the period in the absence of external survey visits; (2) consumers followed during the project showed improvements in the outcomes of independence, integration, individualization, and productivity areas; and (3) agencies in the project gave high marks to the approach for allowing them more responsibility and freedom to improve their services. Finally, the preliminary results of the draft Outcome Review Instrument encouraged the state to effectively replace the compliance survey.

New York has expanded its study of COMPASS to an additional six agencies. It also will continue to improve its Outcome Review Instrument. Attention will be paid to the interrelations of the elements and to a refinement of its structure with a goal of statewide implementation in the summer of 1995.

For more information contact Thomas J. Cuite at (518) 474-3625.

## Standards Review Process of Community Living

*A quality assurance process and related tools*

Area Served: South Carolina

Contact: Susan Thompson, Director
Quality Assurance
South Carolina Department of Disabilities and Special Needs
P.O. Box 4706
Columbia, SC 29240
Phone (803) 737-6533/Fax (803) 743-3593

---

The State of South Carolina operates with a "consultation model" in its quality assurance process for its Standards Review Process of Community Living. This model uses predetermined standards for annual surveys of providers of services to people with disabilities on both hard and soft issues. When surveyors find problems, they recommend changes. The consultation model allows constant interaction and exchange of ideas between providers and the state. Surveyors make quarterly follow-up visits to providers for technical assistance.

Small teams of two-to-three people conduct these surveys which, unless consumers live in their own homes, are unannounced visits to provider sites. Team members talk to staff members and consumers, examine documentation, and observe activities. Administrative surveys are also conducted to look at the managerial components of operating a provider service. Finances, employment practices, and director board records are examples of areas reviewed.

The review process was revised in 1992 to include both outcome-based and process measures. Staff reviewers now look at the person first to decide if desired outcomes are present. If not, the reviewers determine what processes are preventing the outcomes from occurring. Reviewers then make recommendations to the providers for achieving outcomes. Reviewers cite providers immediately for standard noncompliance related to health, safety, rights, and accountability. If cited, the provider must make corrective measures without delay.

Providers, parents, and advocates were all involved in the development of outcome-based changes and now are developing a consumer-satisfaction survey tool. The Director of Quality Assurance attributes this collaboration and the commitment of the state to the design success of the review process.

For more information contact Susan Thompson at (803) 737-6533.

# Utah's Approach to Quality Enhancement

*A non-obtrusive quality assessment tool*

Area Served: Utah

Contact: Georgia Baddley, Director
Program Quality Enhancement
Division of Services for People with Disabilities
Department of Human Services
120 North 220 West, #201
Salt Lake City, UT 84103
Phone (801) 538-4198/Fax (801) 538-4279
Internet number: ggb@email.state.ut.us

---

The goal of Utah's Quality Assurance Plan is "to motivate providers of services for people with disabilities to achieve and maintain the highest standards through an internal quality assurance plan." This plan places decision-making and responsibility at the lowest level and incorporates quality assurance activities into the routine at all levels, including management. The Outcome-Based Survey is a vital part of this goal.

One Quality Assurance team member conducts a non-obtrusive assessment using the Outcomes Survey in the consumer's program settings. Members schedule visits in advance unless there are some concerns relating to a program or individual. Team members use the tool to assess provider services for the consumer based on four standards: personal growth and development; consumer participation in the consumer's Individual Program Plan; consumer participation in Utah life; and the provider Quality Assurance Plan.

Team members score providers of services on these standards. Reports to providers include recommendations for improvement and list the areas in which providers have excelled. A provider that does not meet minimum scores on standards must develop a Plan of Correction. Technical assistance to carry out the changes is available from the Division of Services for People with Disabilities. The Division rewards providers who achieve high scores by reducing the number of surveys. The goal is to induce providers to develop internal quality assurance plans that reflect the values articulated through the Outcomes Survey.

The Outcomes Survey was developed by the Utah Quality Assurance Academy, which is made up of various stakeholders: parents, advocates, state employees, providers, and consumers. The Quality Assurance Advisory Committee was organized by the Academy to oversee and advise on the Quality Assurance Plan. Outcomes Surveys are conducted separately from licensing and health and safety surveys. Contract compliance, a separate function, is conducted at the regional level. Having a variety of players involved from the beginning has been integral to the success of this survey tool, according to the Director.

For more information or materials contact Georgia Baddley at (801) 538-4198.

# South Carolina State Health and Human Services Finance Commission

*An independent agency that oversees quality assurance for social services*

Area Served: South Carolina

Contact: George Appenzeller or Ann Maletic
Division of Quality Assurance
P.O. Box 8206
Columbia, SC 29202
Phone (803) 253-6154/Fax (803) 253-6152

---

The South Carolina State Health and Human Services Finance Commission (the Commission) was established in 1984 to administer Medicaid and federal block grants. A primary responsibility of the Commission is to insure quality of services. However, the Commission is not responsible for direct service; it contracts for services provided under these programs with other government entities.

With the aid of the Human Services Research Institute and the URSA Institute, the Commission developed a quality assurance system for services provided by Social Services block grants. In developing the grant quality-assurance system, five steps were taken: (1) understanding the existing system, (2) developing service standards, (3) developing assessment instruments and systems, (4) developing control and enhancement activities, and (5) establishing good communication structures. Goals for quality assurance were also created. They include assuring capability, good practice, productivity, effectiveness, and serving those most in need.

The Commission helps quality assurance efforts of individual state agencies, including the Department of Special Needs and Developmental Disabilities. These state agencies begin their quality assurance procedures by examining critical outcomes. If the outcomes are not met, the agency examines critical success variables that have been developed as indicators for the outcomes. If this outcome-based process does not provide adequate information, the state agency may revert to traditional standards.

With its new procedures the Commission has separated administrative monitoring from person-centered monitoring. Administrative monitoring is now conducted by the Commission's Division for Program in Monitoring. This separation allows state agencies to concentrate on person-centered monitoring.

For more information contact George Appenzeller or Ann Maletic, Department Head, at (803) 253-6154.

# California Consumer Outcomes

*A statewide approach toward adopting a system of consumer outcomes*

Area Served: California

Contact: Sandy Weiss
Quality Assurance Section, Room 340
Department of Developmental Services
1600 Ninth Street
Sacramento, CA 95814
Phone (916) 654-1976/Fax (916) 654-3666

---

The California Department of Developmental Services (DDS) has set criteria to insure that its quality assurance system is comprehensive and applicable to all individuals receiving DDS services, and that it incorporates the DDS's principles, values, standards, and requirements. DDS staff members have voiced that it is also necessary for the quality assurance system to be consonant with the supported living evaluation process and the move to person-centered planning. A consumer-outcome approach is expected to meet these criteria.

The DDS's desire to move in that direction was supported by the settlement language of the Coffelt class action lawsuit. It specified that consumer outcomes as part of the quality assurance system. In addition, state legislation embodies consumer and family values. These values and outcomes, summarized here, form the core of the quality assurance system:

- A leadership role in service design
- Needs and choices met at each stage of life whatever age or disability
- Services and supports available in home community
- Same opportunities for everyday living patterns as persons without disabilities
- Making choices in all life areas
- Opportunities for integration into the mainstream of life in their home communities
- Parents and family members respected and helped to build circles of support
- Same rights and responsibilities as all other individuals
- Safe, stable and healthy environments
- Services and supports develop competencies and greater self-sufficiency, independence and productivity, so that people can lead typical lives.

DDS has developed outcome oriented standards based on these values. Consultants Allen, Shea and Associates are working with DDS regional centers, developmental centers, consumers, families, service providers, and community members to develop procedures for the use of these standards. A work group is also working toward defining needed licensing and contract changes to align the system with the new standards and procedures.

For more information contact Sandy Weiss at (916) 654-1976.

# INNOVATIVE PRACTICES

## Service Agency Development

## National Management Mentoring Project

*A managerial training and technical assistance project*

Area Served: United States

Contact: Cary Griffin, Executive Director
Center for Technical Assistance and Training
1325 South Colorado Boulevard, Suite 700
Denver, CO 80222
Phone (303) 753-8020/Fax (303) 753-6364
Internet 74243.2567@compuserve.com

---

Many organizations serving persons with developmental disabilities lack resources for the internal improvement needed to provide high-quality services. The National Management Mentoring Project (NMMP) seeks to address such needs for rehabilitation agencies without cost to the agencies.

Each year since 1992 the project has selected five rehabilitation agencies to participate in individualized managerial training and technical assistance. Funded by a three-year contract from the Rehabilitation Services Administration, the Center for Technical Assistance and Training (CTAT) administers the project. CTAT uses a method called "Human Resource Development" that combines on-site classroom training, issue-specific consultation, and field demonstration focused on organizational change and development.

CTAT staff members visit each selected agency four times a year. Each visit introduces at least one "development track" customized to address specific agency-defined challenges and consumer concerns. These development tracks look at values and missions, corporate culture, communication, management and supervisory skills, and self-directed teams. During the process an annual improvement plan is created. Additionally, staff members from each agency attend an annual leadership conference in Denver to discuss project impacts and to learn from CTAT staff and other business consultants.

For more information contact Cary Griffin at (303) 753-8020.

# Quality Team Approach

*A continuous quality improvement approach to services*

Area Served: Harleysville, PA

Contact: GiGi Malinchak
Indian Creek Foundation
P.O. Box 225
Harleysville, PA 19438
Phone (215) 721-3120/Fax (215) 721-3128

---

Improving the quality of internal services can be a foreboding task for many agencies that provide services for persons with developmental disabilities. Indian Creek Foundation, one such agency, found that the continuous quality improvement (CQI) methods of W. Edwards Deming offered the needed structure and support to begin an in-house quality enhancement program.

In 1993, Indian Creek began sending personnel to a local technical school's course on total quality transformation. This initial group of staff members formed the first team. It focused on communication within the agency and became the steering committee for other teams as they developed. This initial team also spearheads the training process for the organization by offering quarterly, in-house voluntary training sessions on CQI ideas. As teams develop to work on projects, the initial team offers continued training and technical assistance.

Through CQI, Indian Creek has initiated a program for increased communication within its organization. Currently, a CQI project is focusing on integrating value-based gentle teaching methods into consumers' annual plans.

For more information contact GiGi Malinchak at (215) 721-3120.

# Rings of Operation Structure

*A consumer-focused organizational structure*

Area Served: Wyoming

Contact: Gary Hudson, CEO
Community Entry Services
2441 Peck Avenue
Riverton, WY 82501
Phone (307) 856-5576/Fax (307) 857-6901
Internet hudcsl@aol.com

---

To increase the quality level of services or to place the focus of services on the consumer, organizations often must redesign their operational structures. Community Entry Services (CES), a provider of residential and vocational services, has done just that.

In 1992 CES revised its mission statement to reflect the growing importance of consumer empowerment and focus; thus it looked at the way services were delivered. After examining the total quality management methods and upside-down organizational charts, CES created a new consumer circular-operation chart in which rings revolve around the center. This ring format better defines the consumer-focused philosophy of the organization:

1. Center: consumers.
2. Support teams, one for each consumer.
3. Direct-service staff members.
4. Support staff and management.
5. Board of directors.
6. Outside funding sources and outside influences on CES.

All rings are interdependent and in an ongoing state of flux. Planning and budgeting processes are also intertwined with this structure. CES still maintains a more traditional hierarchy for its internal personnel. Thus staff members clearly understand by whom they are supervised and where to go with personnel issues.

At the heart of the "rings" structure is the person-centered planning process and the use of consumer support teams. These teams include family, friends, advocates, and case managers. Without the new structure, consumer support teams would not have the power to make things happen for the consumer. The outcome of the redesigned structure has been that consumers served by CES are more involved in their communities and enjoy an increased quality of life. Additionally, CES has adopted an employee team approach from total quality management.

Patterson and Associates in Arizona, and Kaposia, Inc. in Minnesota have helped CES in its restructuring process. They can be contacted at (602) 743-9552 and (612) 224-6974, respectively. For more information about CES contact Gary Hudson at (307) 856-5576.

# Performance-Based Contracting Project

*An outcome-based alternative to ICF-MR quality assurance*

Area Served: Minnesota

Contact: Bob Meyer, Assistant Director or
Jan Menke, Outcome-Based Consultant
Division for Persons with Developmental Disabilities
Minnesota Department of Human Services
444 Lafayette Road
St. Paul, MN 55155
Phone (612) 296-2160/Fax (612) 297-4692

---

The State of Minnesota is embarking on an innovative demonstration project: Performance Based Contracting. Its purpose is to develop and evaluate an effective person-centered demonstration model as the basis of contracting for and assessing service sites. The project will compare the demonstration approach with existing process-based approaches to establish and assure quality in ICF-MR and other government-financed programs for people with developmental disabilities.

Five service provider organizations across the state have been selected as initial demonstration projects. Participating service providers will work cooperatively with county agencies, advocates, consumers, families, and other members of local communities to develop and implement projects.

Minnesota's Department of Human Services (DHS) foresees the demonstrations as lasting up to four years. The projects are expected to improve providers' abilities over time to: (1) offer a wider array of choices to consumers; (2) increase consumer satisfaction with services; (3) achieve and measure needed outcomes; and (4) replace process requirements with performance on things that matter to people. At the end of the demonstration period, the projects may either continue as ICFs/MR, or convert to home and community-based services.

In these projects, DHS will waive some state and federal rules and regulations. The waivers will reduce paperwork and process requirements that do not directly enhance the quality-of-life of service recipients. DHS also expects the waivers to increase program flexibility to achieve desired client outcomes without jeopardizing health and safety. The Health Care Financing Administration will help in funding the evaluation, training, and technical assistance activities of this project.

For more information contact Bob Meyer at (612) 297-0307 or Jan Menke at (612) 296-1090.

## Homeward Bound CQI

*A continuous quality improvement program*

Area Served: Minneapolis/Saint Paul, MN

Contact: Lori Merriam, PRC-Training/Communications
Homeward Bound, Inc.
4741 Zealand Avenue North
New Hope, MN 55428
Phone (612) 535-6171/Fax (612) 535-1608

---

Homeward Bound, a nonprofit provider of residential services to individuals with severe mental and physical disabilities, has committed itself to major service reforms focused on providing opportunities for all service recipients to receive the supports they need in homes of their own. To improve the ongoing program and support the major organizational changes that lie ahead, Homeward Bound is setting up a quality management program based on the philosophies of W. Edwards Deming and other quality management leaders. Homeward Bound refers to its program as "Continuous Quality Improvement (CQI)."

The CQI program was initiated by Homeward Bound board member Kristine King of Quality Process Associates. Ms. King brought her quality management experience to Homeward Bound through CQI training sessions. CQI training on the use of statistics, team building, problem solving, and CQI philosophies began with managers and is working its way to all employees. This training is conducted in three-hour sessions, over four days, in groups of 20 employees.

An executive steering group sets up teams of employees, giving them clear missions and goals. Teams develop methods of solving problems, designing strategy, and planning for operations based on their missions and goals. Before teams carry out ideas, they pass ideas by the steering group. Each team has a team leader who works exclusively on the team project. Currently Homeward Bound is developing facilitators for teams with a train-the-trainer approach.

Quality management initiatives of this type generally are not fully set up for three-to-five years. Homeward Bound, however, has already seen evidence of its effects on the agency, in for example, in employees who seek increased responsibilities, and vendors such as transportation organizations who are increasing their cooperation.

For more information contact Lori Merriam at (612) 535-6171 or Kristine King at (612) 561-2428.

# Service Enhancement

*A voluntary support service*

Area Served: Connecticut

Contact: Joseph Harrison-Becker or
Dennis Mitchell
Service Enhancement Unit
Connecticut Department of Mental Retardation
90 Pitkin Street
East Hartford, CT 06108
Phone (203) 725-3935/TDD (203) 725-3826/Fax (203) 566-3680

---

Supporting a person with developmental disabilities to live the life he or she wants is a main purpose of service providers. Connecticut DMR's Service Enhancement Unit (SEU) supports providers of service in this purpose.

Mutual trust and respect enhance good relationships. The SEU considers ways of relating with support providers given the values of the department - "we strive to treat support providers in the ways we wish them to treat people with disabilities." It follows that interaction with the SEU is voluntary. Ways of enhancing services are choice-driven, individualized, and negotiated between the SEU and the support provider.

The SEU offers support providers options in the enhancement methods they may undertake. Sometimes novel approaches to service enhancement are created through the negotiation process. The approaches to service change most often chosen are the Values Exploration Workshop (VEW) and the Service Quality Review Process (SQRP).

The VEW is a 20-hour exploration of values by providers of service. SEU facilitators lead groups of 15-30 persons to reformulate their thinking about what presence, participation, choice, respect and dignity, competence, good relationships, and the quality of life mean. Examples of questions considered are: "What do these ideas mean?", "Why are they important?", "What do they mean in relation to the lives of people with disabilities you support?". Participants gain wisdom and new approaches to service provision from peers.

The SQRP is a volunteer-based service assessment, brainstorming, and action process. Teams of individuals speak to persons with disabilities, their families and friends, service staff and others. The team also spends time at service environments to see what life is like for everyone involved. Later, the team and support staff meet to discuss impressions of the service, what everyone saw and heard, and to create a picture of the services in written form. Plans and actions to change service practices are voluntarily initiated by support providers based on the new information.

*A Guide to Service Quality Review, The Service Quality Review Process,* and *Values Explorations* can be obtained free of charge by contacting the SEU at (203) 725-3935.

# Oregon System of Continuous Quality Improvement

*Statewide support for quality improvement in the field of developmental disabilities*

Area Served: Oregon

Contact: Meredith Brodsky/Darla Wilson
Paradigm Systems, Inc.
P.O. Box 967
Salem, OR 97308-0967
Phone (503) 363-8609/Fax (503) 378-1979

---

Implementation of the philosophy of continuous quality improvement is a major goal of the State of Oregon Office of Developmental Disability Services. For five years, staff members at the State Office have worked with Paradigm Systems to develop Oregon's System of Continuous Quality Improvement (CQI) for people who work in the field of developmental disabilities. As part of a contract to Paradigm Systems, the state offers the following services to residential and vocational staff and administration, case managers, and county mental health programs:

(1) Surveys: Surveys have been developed to help providers look at the quality of their services. Surveys include an interview protocol for people with developmental disabilities, a Satisfaction survey for family members, a Staff Satisfaction survey, a Management Practices survey, and surveys for program staff in residential and employment programs. Two new surveys have been added this year: Supported Living and Alternatives to Work.

(2) Training: To help CQI programs get started, Paradigm Systems offers half-day, full-day, or two-day on-site training on the philosophy of CQI, Oregon's CQI seven-step improvement process, and technicques that promote teamwork. Oregon encourages administrators, family members, case managers, and support staff to attend training together so they share a common understanding of this approach and its focus on quality.

(3) Facilitation: Case managers, county mental health programs, and residential and employment providers can request a trained facilitator to help them use Oregon's System of CQI. This person facilitates either single or multiple meetings.

(4) Technical Support: Paradigm Systems produces a quarterly newsletter, a handbook on the continuous quality improvement process, and telephone support to Oregon provider agencies.

(5) Best Practice: This manual focuses on innovative and exemplary approaches to quality in the field of developmental disabilities. Providers, advocates, or state personnel nominate entries. The first edition of this "Best Practices Manual" is being reprinted; a second "Best Practices II Manual" will be available soon.

Paradigm Systems is currently working with the Oregon Office of Developmental Disability Services to look at the impact of a philosophy of CQI on services in Oregon. For further information call (503) 363-8609 or fax requests to (503) 378-1979.

# Person-Centered System Design Project

*A system-wide assessment and planning process*

Area Served: Minnesota

Contact: Angela Amado, Executive Director
Human Services Research and Development Center
357 Oneida Street
St. Paul, MN 55102
Phone (612) 227-3292

---

Many criticisms of the "human services system" center on the fact that agencies, systems and services often are not designed to serve the people who are dependent on them but instead to serve the purpose of professionals, regulatory and funding bodies, and the existence of "the system" itself. Many professionals, aware of these weaknesses, would prefer to operate services differently, but lack the structured methods to do so. While an agency that provides services may be able to improve many of its own practices, without a system-wide understanding, direction, and plan there is still a limit on what can happen in the lives of individuals who receive services.

The Human Services Research and Development Center (HSRDC) has been awarded a one-year grant (with possible continuation for a second year) from the Emma B. Howe Foundation to support system-wide planning in the Faribault-Martin Counties of Minnesota. When proposed in 1993, all 11 major providers of services to people with developmental disabilities in the two-county area agreed to participate in this system-wide assessment and planning process.

The project uses an agency change model called "Framework for Accomplishment," written by John and Connie O'Brien. The system-wide analysis allows participants (1) to assess the quality of services provided throughout the system by examining the lives of individuals served and deciding desirable futures for each; (2) to develop a clear vision for system design based on person-centered values; and (3) to determine methods and constructive actions to take at the agency and system level to support more desirable, individualized lives and futures for persons who receive services.

HSRDC will continue to work with the participating agencies to set up the constructive actions and methods of the course for one to two years. People involved include individuals with developmental disabilities; family members; board members; direct care, management, county and state staff members; and community members. This project began late fall of 1994.

For further information contact Angela Amado at (612) 227-3292.

# INNOVATIVE PRACTICES

## Systemwide Quality Enhancement

# Continuous Quality Improvement in New Hampshire

*A state agency initiative to empower consumers and direct-care workers*

Area Served: New Hampshire

Contact: Margaret Aubin, Program Planning & Review Specialist
Bureau of Developmental Services
Division of MH/DS
105 Pleasant Street
Concord, NH 03301
Phone (603) 271-5032/Fax (603) 271-5058

---

In adopting the ideas of continuous quality improvement (CQI), New Hampshire's Bureau of Developmental Services seeks to empower consumers with developmental disabilities and their direct care workers.

The Bureau sponsors, through the state's twelve area agencies, distribution of Dr. W. Edwards Deming's ideas on quality enhancement, emphasizing the importance of building in quality from the start rather than depending on later monitoring to find deficiencies. In New Hampshire's application of this approach, quality is defined by the consumer and becomes the responsibility of the consumer's support persons. Support persons are encouraged to identify issues and problems requiring attention and to expect appropriate assistance in resolution.

Managers across the state attended two-day seminars on continuous quality improvement. These seminars stress values and new perspectives on organizations and attitudes. Seminars are followed by monthly facilitated discussions to deepen participants' understandings of CQI theory and to examine, in a collaborative environment, participants' efforts to apply CQI. Tools to implement the theory are introduced and used.

The Bureau identified three emerging outcomes from New Hampshire's program: (1) continuing high attendance at monthly discussion meetings by provider executives, (2) increasing interagency networking, and (3) moving from traditional quality assurance reviews to collaborative self-assessment.

For more information contact Margaret Aubin at (603) 271-5032.

# Consumer Empowerment Project

*A consumer-focused quality enhancement project*

Area Served: New York State

Contact: Joel Altschul, Assistant Director
Bureau of Management and Program Evaluation
Division of Quality Assurance
New York State Office of MR/DD
44 Holland Avenue
Albany, NY 12229
Phone (518) 474-8007/Fax (518) 486-1108

---

The goals of New York State's Consumer Empowerment Project are improving communication between consumers and agencies that provide services, and improving the quality of life for consumers. With the funding aid of the New York State Developmental Disabilities Planning Council, the Division of Quality Assurance of New York State's Office of Mental Retardation and Developmental Disabilities has undertaken this multifaceted project.

First, the project has redesigned its quarterly publication, *The Quality Assurance Network*, with a consumer focus. It provides a forum for discussing issues related to providing services for people with developmental disabilities. Over 5,200 people nationwide receive this publication.

Second, the project developed the Consumer Opinion Questionnaire (COQ) with the help of hundreds of consumers, parents, providers, and advocates. It is a tool for agencies, advocates and consumers. Its purpose is to include the opinions of consumers in the quality assurance process. COQ is voluntary, can be modified, and can be done anonymously. A video tape is available to accompany the COQ, as is a toll-free hot line.

Third, the Consumer Empowerment Project began piloting third-party citizen/consumer monitoring in January 1993. The project conducts this unobtrusive evaluation through interviews and observations; and it does not look into records and other confidential areas. Called CARE (Consumer Advocate Review and Evaluation), it seeks to fully include consumers in the survey process. Some consumers cannot read or write so there are no written check lists for surveyors to follow. The absence of check lists helps to keep the CARE survey from taking on a regulatory feeling. In addition, the project provides extensive training and apprenticeship periods to promote greater consumer participation. Surveyed agencies receive written reports of CARE findings and recommendations.

For more information or materials contact Joel Altschul at (518) 474-8007.

# Certification Project: Agencies Working Together In Partnership

*A program certification process*

Area Served: Missouri

Contact: Kate McClain, Program Coordinator
Division of Mental Retardation and Developmental Disabilities
Missouri Department of Mental Health
P.O. Box 687
Jefferson City, MO 65102
Phone (314) 751-8674

---

In past years, the quality of residential services for persons with developmental disabilities typically has been measured by input and process indicators rather than by achievement of desired outcomes. Now, however, a new paradigm has emerged which is based on continuously seeking to improve the quality of services provided to people with disabilities.

To address this changed perspective, the Missouri Division of Mental Retardation and Developmental Disabilities (DMRDD) has developed an initiative called "Certification Project: Agencies Working Together In Partnership." This project is based on the precept that ...

> ...to provide quality services and supports requires a partnership between DMRDD and its contracted providers. The individual with developmental disabilities and/or family will determine our effectiveness in meeting their needs and requirements. Individuals being supported and their families should have an ongoing role in monitoring the quality and effectiveness of [the] supports provided.

Missouri's certification project is intended to reorient DMRDD's quality assurance activities to continuous improvement in the performance of agencies to achieve valued outcomes for people with developmental disabilities. The agency's aim is to establish a partnership with service providers so that "services and supports provided are within the context of the individual's preferred lifestyle."

Missouri's certification model is a continuous-loop, feedback-driven process. It consists of an outcome-based survey; the development of an enhancement plan based on survey feedback; technical assistance and training to assist provider agencies; and ongoing reviews of provider agency performance. Biennial, formal certification surveys are complemented by family and consumer reviews of agencies.

For more information contact Kate McClain at (314) 751-8674.

# HCBS Waiver Quality Assurance

*A quality assurance approach for HCBS*

Area Served: Wisconsin

Contact: Ken Golden, Program Manager
Developmental Disabilities Office
Wisconsin Department of Health and Human Services
1 West Wilson Street
P.O. Box 7851
Madison, WI 53707-7851
Phone (608) 266-1520/Fax (608) 266-0036

---

Medicaid funding of Home and Community Based Services (HCBS): an alternative to ICF-MR or nursing home care. It enhances a state's capacity to provide individually responsive services in integrated community settings. Most states now have one or more Medicaid waivers to provide HCBS.

Wisconsin's Medicaid HCBS waiver program long has been a source of information and technical assistance for individuals and agencies in other states that are interested in HCBS programs. Modeled after its state-funded Community Option model, Wisconsin's HCBS program has worked toward building in quality through a menu of services approach. This approach focuses on each individual's needs and preferences.

Beyond the effort to address quality issues from the planning stage onward, Wisconsin's state waiver team maintains ongoing oversight of HCBS recipients' care through frequent personal contacts. In the past year, staff members of the state waiver team visited more than one-half of all HCBS recipients. They met with families and service providers and talked with each individual receiving HCBS to decide their satisfaction with their current circumstances and services.

Although staff review compliance with basic regulatory standards during team visits, attention is directed to individual quality-of-life indicators such as community participation and integration and opportunities for personal choice. The state oversight emphasis is on identifying and providing needed technical assistance and support to improve service quality, rather than on compliance enforcement. Waiver team activities supplement, but do not supplant, quality assurance efforts by case managers and others at the local level.

For additional information contact Dennis Harkins, Director, or Ken Golden at (608) 266-1520.

## Standards for Providers of Services

*A set of state standards combined into one chapter of rules*

Area Served: Iowa

Contact: Ruth Schanke, Bureau Chief, Bureau of QA and Support
Division of MH, MR, and DD
Hoover State Office Building
Des Moines, IA 50319
Phone (515) 281-6221/Fax (515) 281-4597

---

The State of Iowa has combined its provider standards for Community Mental Health Centers, other mental health providers, case management, and Community Supervised Living Arrangements into one standards chapter. Chapter 24 includes a section of core standards that are unique to individual programs. The standards also have service definitions that are consistent across programs.

Consolidated monitoring is another advantage of the standards. The state coordinates the surveys to occur once every three years. Quality assurance and quality improvements are spelled out for agencies in a way to help them establish outcomes, then use those outcomes to help make needed changes or improvements. They include a process for self-assessment of the achievements of provider goals and objectives. The rules require the use of a program evaluation to establish future program goals and objectives.

The Division of MH, MR, and DD is currently working on accrediting by services instead of providers. This will fit in with managed care currently being carried out in the state for all Title XIX mental illness services.

Additionally, in 1992, Iowa added a Medicaid Home and Community Based Services Waiver for persons with Mental Retardation (HCBS/MR) to its array of services offered to citizens with mental retardation in Iowa. Due to the individualized service structure of this waiver, the methods used to assess program quality were examined. A pilot project has been set up to explore outcome-based standards as a tool for measuring providers' service quality.

Through an agreement with the Accreditation Council On Services for People With Disabilities (the Accreditation Council), two educational mock surveys have been conducted at two provider agencies. Each pilot involved Accreditation Council, Iowa waiver, and provider staff. Using the Accreditation Council's "Outcome Based Performance Measures" (1993), each pilot team conducted survey procedures. This allowed both the HCBS/MR staff and the provider staff to experience the survey process and learn about its application.

Pilot project activities were funded by providers who volunteered to participate. These pilots have allowed HCBS/MR staff and provider staff the opportunity to understand this new method of assuring service quality. Iowa will soon pilot two new projects that will compare the Accreditation Councils Outcome Based Performance Measures with Iowa's own outcome measures.

For more information regarding this HCBS/MR pilot project or the Standards for Providers of Service, please contact Ruth Schanke at (515) 281-6221.

# New York State Commission on Quality of Care for the Mentally Disabled

*An independent commission to administer protection and advocacy services and influence quality*

Area Served: New York

Contact: Clarence J. Sundram, J.D., Chairman
New York Commission on Quality of Care
for the Mentally Disabled
99 Washington Avenue, Suite 1002
Albany, NY 12210-2895
Phone (518) 473-4057/Fax (518) 473-6296

---

Since 1978, New York state has had an independent Commission on Quality of Care for the Mentally Disabled. The Commission is broader in scope and influence than most state Protection and Advocacy services (P & As). The state statute has enabled the commission to exercise broad oversight within the mental hygiene system and to serve as an advocate for people with disabilities. The Commission has a seat in the Governor's Cabinet, allowing it substantial influence on policy-making. The Commission, as an independent overseer, also (1) investigates all unusual deaths, abuses, and complaints; (2) is an independent source of advice for state policy makers; (3) conducts policy analysis and cost effectiveness studies and fiscal investigations; and (4) distributes findings through published reports and a widely distributed newsletter.

The Commission goes beyond investigations to make positive changes in the delivery system. For example, the Commission's Surrogate Decision Making Committee Program hastens the process of getting medical services to consumers who cannot make decisions independently.

The Commission publishes a series of case studies, *Could This Happen in Your Program?* Available to any interested party, the studies present brief analyses of cases that have been investigated. The investigative findings, corrective actions, and lessons learned are intended to serve as inservice training tools and to engage facility staff members in discussions of their policies and practices in answer to the question, "Could this happen here?"

Clarence Sundram, Chairman, sees the Commission as influencing the quality of community services in three ways: (1) the Commission increases access for people with mental disabilities to community health care; (2) it promotes desegregation for people with disabilities in communities; and (3) it conducts studies of community-residential programs to help to connect quality of life issues with state policies.

For more information contact Clarence Sundram at (518) 473-4057.

# Strategic Plan for Revitalization of Mental Retardation Services in Philadelphia

*A citywide systematic plan to enhance quality*

Area Served: Philadelphia, PA

Contact: Michael Covone, Acting Director
Mental Retardation Services
Office of Mental Health and Mental Retardation
City of Philadelphia
1101 Market St., 7th Floor
Philadelphia, PA 19107
Phone (215) 592-5489/Fax (215) 592-5484

---

Efforts to assure and enhance service quality for persons with developmental disabilities may benefit from a systematic planning process involving all interested parties. Philadelphia, Pennsylvania is advancing such an effort.

Representatives of consumers and their families, advocates, service providers, and the governments of Philadelphia and Pennsylvania conceived the Community Collaboration. They formed, in Philadelphia, a plan to restructure services to meet the needs of all persons with mental retardation in the city. The product of this effort is a recently published strategic plan identifying intended beneficiaries and specifying 42 outcomes for the next several years.

Based upon the most valued aspects of people's lives, the plan is shaped by a commitment to use best practices to support these values in the lives of persons with mental retardation. The plan documents how each intended outcome will support one or more identified values.

In Philadelphia's Collaboration, outcomes are grouped into one of three clusters. Responsible parties assure the achievement of outcomes and a planning track manager is responsible for the implementation of each cluster. The Philadelphia Office of Mental Health/Mental Retardation and the Pennsylvania Office of Mental Retardation share general responsibility for carrying out the plan. A Planning Advisory Committee, appointed by the Director, Philadelphia Office of MH/MR, will monitor progress and assist plan compliance.

For additional information contact Michael Covone at (215) 592-5489.

# Wyoming Quality Review Project

*A person-centered approach to systematic change*

Area Served: Wyoming

Contact: Jeanne Thobro, Executive Director
Wyoming Protection and Advocacy System
2424 Pioneer Avenue, Suite 101
Cheyenne, WY 82001
Phone (307) 632-3496/Fax (307) 638-0815

---

The Wyoming Protection and Advocacy (P&A) System is sponsoring a project to enhance the quality of community services throughout Wyoming. The state P&A has contracted with Patterson and Associates to do the project. Using its "Quality Review Process," the process is based on the philosophy that management of quality services cannot depend on the measurement of deficiencies alone but must have access to measures of achievement as well.

Two stages of the project are near completion: (1) a statewide assessment of each of Wyoming's nine regional service providers that produced written reports, for providers and the P&A agency, of each provider's indicators of quality and barriers to improvement; and (2) three volunteer provider agencies engaging in a personal futures-planning process with each of two consumers served by each provider agency. In addition, each of the three provider agencies conducted forums of consumers and family members to discuss the meaning of quality of life. From these activities direct-care staff members planned how to support consumers in achieving their desired personal outcomes. Provider agency management planned how management could best support its staff members in such efforts.

Terry Cooper, Executive Director of Arc Regional Services, one of the three volunteer agencies, hopes that Wyoming will incorporate the personal futures planning technique of goal development into the State's Individualized Planning Process. She is pleased with the change the Quality Review Project has brought to her agency and may be called for more information at (307) 742-6641.

For more information on the Wyoming P&A project contact Jeanne Thobro at (307) 632-3496, or Joseph Patterson, Patterson and Associates at (602) 743-9552.

# The Vermont Crisis Intervention Network

*A statewide crisis service*

Area Served: Vermont

Contact: Patrick Frawley, Coordinator or
Elia Vecchione, Executive Director
Resources for Community Living, Inc.
R.R. # One, Box 600
Moretown, VT 05660
Phone (802) 496-3844/Fax (802) 496-3850

---

The Vermont Crisis Intervention Network is a three-tiered service delivery system intended to prevent and treat any crisis experienced by a person with mental retardation within Vermont. Since March of 1991 a total of 102 individuals has been served. The program is collaborative in that all mental health centers from Vermont participate, as do staff from the Vermont Division of Mental Retardation. Vermont has no institutions for persons with mental retardation, so such a project is essential to maintain people within the community.

Within Level I of the program, key clinical staff from each of Vermont's 13 Community Mental Health Centers gather for a monthly meeting. At this meeting, challenging or difficult clinical cases are reviewed, usually at a point before an actual crisis. Training sessions are also presented at this meeting by area experts. This monthly meeting allows individuals from agencies throughout Vermont to come together to support each other, and also learn from each other's experiences. The prevention orientation attempts to reduce the number of crises within the state.

Level II of the program provides on-site psychological or psychiatric consultation to agencies and individuals experiencing difficulties. In addition, experienced crisis-support direct-service staff members are available to provide hands-on instruction and support. This level of service also functions to prevent crises from escalating beyond the management capabilities of the local agencies.

Two residential crisis spaces are provided within Level III of the program. These are within residential programs located in rural houses and are staffed 24 hours by Crisis staff. These spaces are reserved only for those individuals whom either must leave their current home and have nowhere to go, or for people who require a diagnosis and evaluation period away from their homes. Usually people stay within these homes from 30 to 60 days.

For more information contact Patrick Frawley at (802) 496-3844.

# INNOVATIVE PRACTICES

## Values Infusion

# It's About Lifestyle Choices

*Training focused on consumer choice*

Area Served: Delaware

Contact: Hope Ellsworth, Training Administrator
Delaware Division of Mental Retardation
Route One, P.O. Box 1000
Georgetown, DE 19947
Phone (302) 934-8031, Ext. 346/Fax (302) 934-6193

---

Traditional human service systems develop programs and put people into them. A new way of providing services that is being considered across the country that suggests starting the system with individuals and building services around them. All people need to be provided settings where their important lifestyle choices can be met. "It's About Lifestyle Choices" is a training program that promotes such choice.

The program is conducted for providers, professionals, direct-care workers, and parent advocacy groups. It takes a lighthearted look at the current system and examines specific changes that could be made by each person who participates in the training. The focus is on one-on-one grassroots change. Choice is a key value articulated through the training for participants to use in looking at ways to detect consumers' desires. Training is conducted in one-day workshops devoted to overviews of the following topics:

- new directions in service delivery affecting the person;
- new directions in service delivery affecting the system;
- how the system has made people fit into the system;
- moving beyond readiness;
- choices;
- labeling "the label trap"; and
- personal commitments for change.

The training was developed by the former Delaware Community Living Coalition with the help of Michael Smull, University of Baltimore. The Coalition is now merged with the Delaware Advocacy Coalition.

"It's About Lifestyle Choices" receives no special funding. Volunteers conduct the training and their employers allow them to conduct training during workshop hours. Employers also donate supports, such as copying services.

For more information contact Hope Ellsworth at (302) 934-8031.

# Alaska Service Principles

*A set of statewide service principles*

Area Served: Alaska

Contact: Mike Renfro, Program Administrator
Developmental Disabilities
P.O. Box 110620
Juneau, AK 99811
Phone (907) 465-3370/Fax (907) 465-2668

---

Alaska has several programs to assure quality in community services for people with developmental disabilities, all based on Alaska's nine service principles.

These nine principles range from "services are the result of ongoing planning" to "services are culturally appropriate." Information from state staff members, the public, parents, and service providers have aided in several refinements of the principles. Each year the principles are presented to about 800 parents at a state conference, and are distributed to service providers, parents, and planning councils.

Consumers entering the service system complete an initial evaluation questionnaire related to the Service Principles. If the consumer is not satisfied, funding is not released and the state looks into what can be done to satisfy the consumer. This tying of funding to the Service Principles allows the state to insure quality of services from the onset.

Mike Renfro, who feels it is hard to separate the Service Principles from the entire service delivery system, says the Service Principles are the foundation for everything else in the system. He stresses that having funding attached to the consumer is essential to insure quality. Service providers know that consumers can easily move to another provider if service quality is low.

For a copy of the booklet, *Service Principles*, or the video tape, *Individualized Services*, or for general information contact Mike Renfro at (907) 465-3370.

# Tennessee Vision 2000

*A statewide conceptual plan for the future*

Area Served: Tennessee

Contact: Janice L. Spillman, Director, MR Planning
Department of Mental Health and Mental Retardation
Gateway Plaza, 11th Floor
710 James Robertson Parkway
Nashville, TN 37243-0675
Phone: (615) 532-6530/Fax (615) 532-6964

---

For years, the mental retardation service system developed programs and put people into them. That is no longer the way the State of Tennessee develops services for people with mental retardation/developmental disabilities. In 1993, when the Division of Mental Retardation (DMR) and the State Advisory Planning Committee (SAPC) set out to develop a new plan for future services development, they held public forums across the state to solicit input from consumers and their families, advocates, service providers, and government agencies. From the forums, the DMR and SAPC developed a conceptual plan for the future, *Vision 2000 A New Life for Tennesseans*.

In essence, Tennessee's vision of the future is that persons with mental retardation/developmental disabilities will have supports based on their individual needs and choices. The plan envisions a new system that starts with individuals and builds services around them. The SAPC and the DMR adopted person-centered planning as the mechanism to realize the goals of Vision 2000.

Tennessee proposes to establish several layers of consumer protection and monitoring to insure that clients receive quality services provided by well-credentialed providers. The first step in this pursuit was identification of one service provider in each of three regions to develop a program of total quality management. Training is currently underway.

Tennessee's plans for quality assurance of services for persons with developmental disabilities will focus on consumer surveys, systems analysis, and outcome measurement of the service providers. A Consumer Review Board will be established to assist the state in the development, use, and monitoring of a comprehensive service delivery system for individuals with mental retardation. Primary responsibilities of this board will be to study the effectiveness of programs based on consumer satisfaction evaluations, and to ensure that there is an appropriate use of resources across the system.

For more information contact Janice L. Spillman at (615) 532-6530.

# INNOVATIVE PRACTICES

## Consumer and Citizen Monitoring

# Quality Measurement Instrument Review

*A summary of quality assurance measurement instruments*

Area Served: United States

Contact: Bill Allen & John Shea
Allen, Shea & Associates
1040 Main Street, Suite 200B
Napa, CA 94559
Phone (707) 258-1326/Fax (707) 258-8354

---

As part of its effort to develop the Colorado Program Assessment and Review (COPAR), the Division of Developmental Disabilities contracted with Allen, Shea & Associates (ASA) to examine state-of-the-art and best practices in quality assurance instruments throughout the country.

ASA reviewed 72 instruments in quality assurance measurement. They looked at how these tools compared to the values stated in the Division's mission statement. These values include: friendship and belonging, self-esteem, competencies and talents, decision-making, community inclusion, and satisfaction.

ASA's survey began in Spring of 1992 with a survey of directors of state Arcs, state MR/DD directors, and agencies providing advocacy or other services. In addition, they conducted a general literature search to identify quality assurance instruments. Throughout their search they used a "snowball" technique, asking informants for leads to creators and users of instruments, and to literature in which results were presented.

Among the conclusions of ASA were that most tools have been developed as a method of evaluating services or reviewing compliance with standards; and are concerned with lifestyle, environments, and behavioral characteristics. They also learned that most tools have not: (1) considered alternative methods of data collection for persons who have limited communication skills; (2) been studied to determine reliability or validity; (3) been standardized; (4) focused solely on quality-of-life; and (5) offered interpretive guidelines. ASA additionally found that some instruments included an interview with the person with a disability and some quality-of-life measures.

The review is available as part of the Measurement Tool Survey's *Final Report* from Allen, Shea & Associates for $9.95. For more information call Bill Allen or John Shea at (707) 258-1326.

# Quality Assurance for People Moving

*A quality assurance module for de-institutionalization*

Area Served: Washington State

Contact: Maureen Weeks, Quality Management Program Manager
Washington Department of Social and Health Sciences
Division of Developmental Disabilities
P.O. Box 45310
Olympia, WA 98504-5310
Phone (206) 586-6180/Fax (206) 753-2768

---

In Washington, hundreds of people with developmental disabilities have moved from large institutional settings to community residential programs. In response, the state has developed a quality assurance module to examine health and safety, power and choice, status, integration, relationships, and autonomy of persons who have moved from institutions to the community.

A team consisting of a quality assurance manager and two volunteers question people who have moved about their homes, work, friends, and activities. The team also surveys case managers, families, and residential and vocational program staff members. The goal is to assess the person's move, find out if consumers like where they live, and decide if consumers have the community support they need. A report is then completed and action plans developed to correct any problems. Aggregate trends are analyzed and used to assess state processes for transitioning people.

In 1989, the Division of Developmental Disabilities appointed an evaluation core group to comprehensively review all services provided by the division. From this core group a task force on quality assurance for people moving from large institutions to the community was developed.

The Division of Developmental Disabilities first implemented Quality Assurance for People Moving in January 1990. It is managed and funded by the Division of Developmental Disabilities at a cost of approximately $450,000 per year. Volunteers are reimbursed for expenses but are not paid for their services. The Division is now seeking to expand this quality assurance program to additional service areas.

For more information contact Maureen Weeks at (206) 586-6180.

# Oklahoma Advocates Involved in Monitoring (OK AIM)

*A consumer monitoring system*

Area Served: Oklahoma

Contact: Dennis Bean, Programs Administrator
Quality Assurance Unit
Developmental Disabilities Services Division
Oklahoma Department of Human Services
P.O. Box 25352
Sequoyah Memorial Office Building
Oklahoma City, OK 73125
Phone (405) 521-6265/Fax (405) 521-6684

---

As more persons with developmental disabilities return from institutions to their communities, often living in small, dispersed homes, an effective process to insure the quality of their community-based services is required.

An Oklahoma court order to deinstitutionalize persons with developmental disabilities referenced a monitoring process that would increase the involvement of consumers and their families. After reviewing various systems for monitoring service quality, a statewide committee of consumers and staff members selected the Oregon model. The Oklahoma Department of Human Services contracted with the Tulsa Arc to establish and operate a monitoring program, Oklahoma Advocates Involved in Monitoring (OK AIM).

Under the leadership of John Gajda and a statewide committee of consumers, teams of OK AIM volunteers composed of consumers, family members, friends and advocates for persons with disabilities try to assure and enhance service quality. Teams visit provider agencies to evaluate services and suggest improvements, and they gather and report information to assist consumers in choosing between services and providers. Evaluations by OK AIM suggest that providers are responsive to surveyor team suggestions and that direct-care staff often display more positive attitudes toward persons with disabilities because of OK AIM initiatives.

The OK AIM program has developed a handbook containing a total of 26 items in four categories to be used by surveyors in reviewing services to persons with disabilities. The handbook is employed both in the six hours of training provided to all surveyors and as an ongoing resource in conducting reviews.

To obtain further information and materials about OK AIM contact Dennis Bean at (405) 521-6265 or John Gajda at (918) 582-8272

# Team Advocacy Project

*A quality-of-life monitoring program*

Area Served: South Carolina

Contact: Linda Blank, Coordinator
South Carolina Protection and Advocacy System
3710 Landmark Drive
Suite 208
Columbia, SC 29204
Phone (803) 782-0639/Fax (803) 790-1946

---

The South Carolina Protection and Advocacy System (SCP&A) uses an innovative monitoring system that looks beyond health, safety, and regulatory compliance, called the Team Advocacy Project.

The Team Advocacy Project trains volunteers to conduct surprise inspections of facilities using a survey instrument designed to assess the quality of resident living conditions. Volunteers are trained to look at consumer needs, environmental conditions, health, safety, service coordination, and quality of life. Volunteers also survey the basic living conditions of the residence. For instance, they look for humanizing touches such as pictures on the walls. They look to see if residents have places to keep personal belongings and ask themselves, "Would I like to live here?"

After the team of three visits the residence, using the team's observation notes, the Team Advocacy Project Coordinator prepares a report. She then sends this report to the Joint Legislative Governor's Committee on Mental Health and Mental Retardation, and state agencies. The committee asks the residence owner to respond within thirty days, and a re-inspection of the residence is scheduled to see if improvements have been made.

The project is managed by the central office of the SCP&A. It is overseen by an advisory committee with members from various associations and SCP&A. The Team Advocacy Project is funded by a contractual agreement with Department of Mental Health.

For materials or information on the Team Advocacy Project contact Linda Blank at (803) 782-0639.

## Care Review Committees

*A volunteer-based monitoring program*

Area Served: Iowa

Contact: Carl M. McPherson, State Long-Term Care Ombudsman
Kris Bullington, State Care Review Committee Coordinator
Iowa Department of Elder Affairs
914 Grand Avenue, Suite 236
Des Moines, Iowa 50309-2801
Phone (515) 281-5426/Fax (515) 281-4036

---

To insure the quality of community services in Iowa, committees of community volunteers are assigned to every long-term care community facility. These volunteers make periodic unannounced facility visits. Whatever funding source, ownership, or demographic consumer makeup, each long-term care facility licensed in Iowa must have a Care Review Committee to conduct monitoring, offer suggestions for improvement, and help to resolve problems.

The Care Review Committees were designed to reflect the community; thus the Department of Elder Affairs solicits volunteers from all areas of the community. Each facility must have a committee of at least three members, and the goal is a ratio of one volunteer to 15 residents per facility. Currently, there are over four-thousand such volunteers in Iowa.

Volunteers interview residents about their quality of life satisfaction at least once a year and meet quarterly to review their findings and discuss problems. Reports from these meetings are given to facility administrators along with the yearly reports volunteers produce about each resident. The Care Review Committees have no formal authority; they rely on their relationships with the service provider administrator for the resolution of problems. Minutes of their quarterly meetings and reports on the problems addressed are provided to the Area Agencies on Aging.

Carl McPherson, Long-Term Care Ombudsman, administers the Care Review Committee program through the Department of Elder Affairs. He would like to see the volunteers take on roles as change agents for their facilities and move more toward advocacy for the residents. He feels this could be accomplished by adding local ombudsmen to train and guide volunteers and to handle complaints at the local level.

For more information contact Carl McPherson or Kris Bullington at (515) 281-5426.

# Eastern Shores Community Monitoring

*A volunteer-based quality enhancement program*

Area Served: Maryland's Eastern Shore

Contact: Susan Atwood, Director
1500 Riverside Drive
Salisbury, MD 21801
Phone (410) 219-2828/Fax (410) 219-2838

---

Eastern Shore Community Monitoring is a volunteer organization that offers multifaceted services in cooperation with the Eastern Shore Regional Developmental Disabilities Administration and 18 independent nonprofit agencies. A group of parents started Community Monitoring in 1987.

Family members, provider staff, consumers, professionals, advocates, and community members are among the 100 trained volunteers who donate their time to Community Monitoring. Volunteers actively work throughout the nine counties of the Eastern Shore of Maryland to develop positive relationships with agencies, direct care workers, families, and consumers.

Community Monitoring encourages positive lifestyles through Residential Monitoring, Companion Connection, Family Networking, and Lifetime Planning. Residential Monitoring volunteers visit state-licensed homes to promote quality lifestyles. Companion Connection establishes friendships between people with challenges and members of the community, sororities, fraternities, and churches. Family Network provides one-on-one confidential volunteer support to families of people with developmental disabilities. The booklet, *Personal History for Lifetime Planning*, allows families and consumers to record personal information and future aspirations.

All services offered by Community Monitoring are supplements to licensing, intra-agency requirements, accreditation, and other services. Agencies are not legally bound to join in the surveys and activities conducted by Community Monitoring, but all area agencies do participate. Volunteers do not have access to confidential records, procedure compliance reports, or performance standards that are reviewed by other agencies.

An annual grant of $25,000 from the State of Maryland provides funding. This money pays for overhead, travel, and one halftime director. Volunteers may request reimbursement for expenses but seldom do.

For more information or materials, contact Susan Atwood at (410) 219-2828.

# Quality Review Teams

*A quality-of-life monitoring program*

Area Served: Nebraska

Contact: Cathy R. Anderson, Director
Nebraska Developmental Disabilities Division
P.O. Box 94728
Lincoln, NE 68509
Phone (402) 471-2851/Fax (402) 479-5145

---

The Nebraska Developmental Disabilities Division (NDDD) manages a pilot project that uses consumers and other volunteers to conduct nontraditional quality of life reviews with a person-centered, desired-outcomes approach. In June 1991, the Nebraska Legislature passed the Developmental Disabilities Act that included significant changes for people with developmental disabilities. Among these changes was the requirement for the establishment of quality review teams (QRT) in each of Nebraska's six geographic developmental disabilities regions.

The statute specified that each team should consist of four appointed members. Each team must include at least one consumer and one person who is neither a consumer nor a relative of a consumer. No person on these teams may be an employee of a government or provider agency. NDDD reimburses QRT members for necessary expenses incurred in doing QRT duties. Each team will conduct annual quality of life surveys for people with developmental disabilities, investigate complaints, and make recommendations related to residents' quality of life.

Since 1992, NDDD has contracted with the Arc of Nebraska to carry out a pilot project of the Quality Review Teams in two of its six regions. The pilot project has focused on the people living in group homes and agency operated residential settings. 1994-95 funding for the project is $30,000, which includes funding for QRT teams already operating and for expansion of teams into additional communities. NDDD is seeking to fully fund QRT teams statewide through a budget request of $170,000 for the years 1995-97.

For more information contact Cathy Anderson at (402) 471-2851.

# INNOVATIVE PRACTICES

## Community Relationship Building

# Neighborhood Support Project

*A project that supports the inclusion and contributions of people with disabilities in the life of their neighborhoods*

Area Served: Seattle

Contact: Mary Romer/Carolyn Carlson
Residential Technical Assistance Project
Catholic Community Services
1932 1st Avenue, #905
Seattle, WA 98101
Phone (206) 443-9592/ Fax (206) 728-2318

---

The Neighborhood Support Project is a community building effort that focuses on bringing persons with disabilities with people and places in neighborhoods to support the inclusion and contributions of all people into neighborhood life. The project assumes that the presence and participation of people with disabilities is a community and not just a family or systems' responsibility. Many strategies employed and the thinking behind the project has been strongly influenced through consultation with Kathy Bartholomew-Lorimer and through John McKnight's work in the Logan Square neighborhood of Chicago.

Staff members of the project work in partnership with the Fremont Neighborhood Council. This neighborhood association in Seattle is committed to discovering the capacity of the neighborhood to welcome and include people who are isolated and disenfranchised. The general focus of this partnership is to learn together what it may take to seek out, welcome and offer support to all members of the neighborhood. For the Fremont Neighborhood Council, staff members spend time getting to know the people with disabilities and their families who live in the neighborhood. Once a sense of people's gifts, capacities and interests is attained, members of the Neighborhood Council are enlisted as *introducers* to people, associations, and places in the local community where common interests can be shared. Staff members then act as *guides* to support the person's initial participation with ordinary citizens in typical neighborhood activities, events, and associations. The intent is that the staff will shift the ongoing support needed by individuals with disabilities to community members.

In this next year of the project, the principal management has been shifted from the staff of the Neighborhood Support Project to the Fremont Neighborhood Council. The Council has been awarded a grant from the City of Seattle's Department of Neighborhoods to develop a "Time Dollar" project. The project, called "Fremont Time," will be a service exchange venture in which everyone's time will be valued and exchanged equally. Catholic Community Services will subcontract with the Fremont Neighborhood Council so that the Council can directly hire someone to support the participation and contributions of people with disabilities in this effort. The Neighborhood Support Project staff will participate on the steering committee and act as consultants to Fremont Time.

For more information contact Mary Romer or Carolyn Carlson at (206) 443-9592.

## Community Advocate Program

*A program matching volunteers with people with disabilities toward community integration*

Area Served: Hennepin County, Minnesota

Contact: Jerry Mellum, Individual Advocate
Arc of Hennepin County
Diamond Hill Center, Suite 140
4301 Highway 7
Minneapolis, MN 55416
Phone (612) 920-0855/TTY (612) 920-4392/Fax (612) 920-1480

---

Many people with developmental disabilities lack contacts and supports outside the service-delivery system. The Community Advocate Program matches volunteers one-on-one with individuals with developmental disabilities who are making the transition into the community. These volunteers lend personal support and resources.

Hennepin County Community Services and Arc of Hennepin County continue to collaborate on this successful effort. Their cooperation allows for expanded support resources for volunteers including mileage reimbursement, training, continuing education credits, and related emotional and social support.

Volunteers spend several hours, two or three times monthly, with their matches; their relationships, however, may last a lifetime. Each relationship is unique, forged by individual circumstances, personalities, and needs. The volunteer serves variously as companion, individual advocate, links to the community, negotiator, and advisor. Community Advocates help an individual with a developmental disability to learn social and independent living skills as he or she explores their new community with the volunteer. The goals of this partnership are advocacy, community inclusion, protection, and a strengthened community.

For more information contact Jerry Mellum at (612) 920-0855 or Judy Corrao, Volunteer Manager, Hennepin County Community Services, Volunteer Services, at (612) 348-7481.

# INNOVATIVE PRACTICES

## Technical Assistance

## Life Quilters Project

*A project supporting people with challenging behaviors*

Area Served: West Virginia

Contact: Don Kincaid, Project Coordinator
University Affiliated Center for Developmental Disabilities
West Virginia University
Research & Office Park, 955 Hartman Run Road
Morgantown, WV 26505
Phone (304) 293-4692/Fax (304) 293-7294

---

The Life Quilters Project seeks to improve the lives of West Virginians with both mental retardation and challenging behavior who are at risk of losing their community placements or who are in transition from institution to community living. Operating from a person-centered values base and a broad ecological perspective, the project works to enhance the capacity of service providers to create and maintain supports of high quality for this population.

Life Quilters effects services to persons with developmental disabilities at many levels. Organizations are helped to formulate policies and define practices, identify and obtain resources, plan and provide services, design and conduct staff training, and monitor and improve quality. Families, service providers, and interested others are taught person-centered techniques to deal with challenging behavior. Individual consumers are helped to develop new abilities, establish satisfying relationships, and gain personal dignity and respect.

The program follows a four-phase sequence in conducting projects, similar to phases used in many continuous quality improvement programs: (1) plan; (2) learn; (3) do; and (4) evaluate. Critical activities within each project include developing memorandums of agreement, developing personal profiles and plans, assessing service delivery, conducting individual functional analyses, developing work plans, identifying a work group, and evaluating outcomes. Life Quilters offer long- and short-term consultation and positive behavior support training to agencies and individuals. The full commitment of the focus consumer, the consumer's family and the consumer's support-services providers, is considered essential to success. Annual costs of West Virginia's Life Quilter program are near $250,000.

For further information and materials concerning the project, contact Don Kincaid at (304) 293-4692.

# Reaching Up

*Reducing direct-care staff turnover through education*

Area Served: New York

Contact: William Ebenstein, Director
Reaching Up
434 East 52nd Street, Suite 1E
New York, NY 10022
Phone (212) 754-6750/Fax (212) 754-0203

---

"Reaching Up" is a nonprofit organization whose mission is to support the education and career advancement of direct-care workers who provide health, education, and social services to individuals with disabilities. Reaching Up was founded on two principles: (1) that quality care for people with disabilities is dependent on the creation of quality jobs for direct care workers; and (2) that a stable relationship between consumer and skilled, responsive, and compatible direct-care worker is the cornerstone of a quality human services delivery system. Unfortunately, this work force is characterized by high turnover, low wages, minimal training and few career opportunities.

Reaching Up responds by:

- providing, through the Kennedy Fellows Program, scholarships and career mentoring to direct care workers who are enrolled at CUNY and SUNY colleges;
- providing, through the Consortium for the Study of Disabilities, small grants to participating colleges to develop credited training programs in rehabilitation services; each year worker-students enroll in over 50 new courses and sponsored academic programs; and
- providing, through the Center for Workforce Development, technical assistance to human services agencies to develop comprehensive workforce plans and improve relationships between their consumers and direct care staff members.

The purpose of these coordinated activities is to reduce turnover and increase the tenure of direct care workers; increase their skills and job competencies; improve their access to continuing and higher education; create career ladders and other opportunities for career advancement; and improve the quality of services to consumers. Reaching Up has worked with the U.S. Congress to enact legislation that authorized funding for demonstration projects based on the Reaching Up model. It has also worked with the New York State Governor's office to establish an interagency Task Force on the direct care work force. Reaching Up is guided by a public/private partnership that consists of representatives of higher education, state government, public and private human services organizations, unions, and consumer groups.

For more information contact William Ebenstein at (212) 754-6750.

## Developmental Disabilities Training Institute

*A training, technical assistance, and research center*

Area Served: United States

Contact: George S. Baroff, Ph.D., Director or
Tony Dalton, Assistant Director
CB #3370, Carr Mill Annex
University of North Carolina at Chapel Hill
Chapel Hill, NC 27599-3370
Phone (919) 966-5463/Fax (919) 962-5837
TTY: (919) 962-5291

---

The Developmental Disabilities Training Institute (DDTI) was formed by the North Carolina General Assembly in 1963 to provide training and technical assistance to programs serving persons with developmental disabilities. DDTI is housed in the Division of Continuing Education of the University of North Carolina at Chapel Hill, and is supported through a combination of state funds, state and federal grants and contracts, private foundation awards, and training fees.

The focus of DDTI's training is on promoting high quality in the services for individuals with developmental disabilities and their families. Accordingly, the importance of values-integration, inclusion, maximum personal development and the enhancement of social roles is a strong theme in their activities. Training involves many different topics including: sexuality, gentle teaching, counseling, "nonaversive" behavioral techniques, staff/consumer relationships, integrative and supported employment services, case management, person-centered planning, community participation, and customer-driven evaluation. DDTI also provides: (1) consultation, technical assistance, and training for administrators and management personnel; (2) studies systems of services; and (3) evaluation on the quality of services and service systems.

Additionally, DDTI conducts research related to "best practices" and service structures at both a state and national level. A 1988-92 study of "best practices" in integrative employment services for persons produced two monographs, The "*Best Practices" Manual* (1990) and *Outstanding Integrative Employment Agencies: Creativity, Leadership and Commitment* (1992). DDTI also published a *Curriculum on Sex Education and Social Skills Training for Persons with Developmental Disabilities* in 1994. The curriculum is comprehensive, up-to-date and inexpensive. In 1994, DDTI undertook a statewide training effort in support of the implementation of North Carolina's "Ten-Year DD Plan." Lastly, in 1994/95, DDTI undertook a new DD Council-funded project, "Customer-Driven Systems Change." This project will support greater participation of people with developmental disabilities and family members in advocating for improvements in North Carolina's services, staff training and public education.

For more information on DDTI, including published materials, contact Tony Dalton at (919) 966-5463.

# INNOVATIVE PRACTICES

## Personnel Training and Professional Development

# North Dakota Statewide Developmental Disabilities Staff Training Program

*A statewide training program for direct service staff*

Area Served: North Dakota

Contact: Demetrios Vassiliou/Mary Mercer
North Dakota Center for Disabilities
Minot State University
Minot, ND 58707
Phone (701) 857-3047

---

To assure and enhance community service quality for persons with developmental disabilities, direct service staff training is essential. Since 1983, North Dakota has provided such training through a cooperative effort of the North Dakota Department of Human Services (DHS), Minot State University (MSU), and community agencies serving persons with developmental disabilities. North Dakota requires full-time direct service staff to demonstrate knowledge and skills in topic areas addressed in the fourteen training modules and a series of supervised practica. Service providers employ state-certified regional trainers to teach these modules. MSU faculty also offer six workshops throughout the state specific to interests of direct-care staff members.

The seven-step professional developmental sequence through MSU includes: (1) entry level orientation; (2) position-based competency training; (3) a training module Certificate of Completion; (4) an Advanced Certificate of completion; (5) an Associate of Arts in Developmental Disabilities; (6) a Bachelor of Science in Mental Retardation; and (7) a Master of Science in Special Education. Learning options include formal instruction, on-site demonstration, mentoring, and self-study with or without discussion group participation. Staff members may test out of individual modules by demonstration of required competencies.

DHS supports the program by funding service providers and MSU's University Affiliated Program's materials development and training activities. State funding for this project in 1995 is $68,270.

Key program elements include cooperation among state DHS, MSU, and service providers; comprehensive, but flexible, training materials; a statewide system of individual training records; state standards for direct service staff training; a career training sequence leading to academic degrees; and program consistency through time and across North Dakota.

For additional information contact Demetrios Vassiliou, Director of Field Training Programs, or Mary Mercer, Field Training Coordinator, at (701) 857-3047. The entire series of training modules may be purchased for $80 by contacting Dr. Vassiliou.

# Kennedy Fellows Mentoring Program

*A mentoring program for direct-care workers who are also students*

Area Served: New York

Contact: Lyda Clifton, Coordinator
New York State Consortium for the Study of Disabilities
535 East 80th Street
New York, NY 10021
Phone (212) 794-5673/Fax (212) 794-5706

---

In recent years, inadequate direct-care workers' training and high direct-care worker turnover has prompted much discussion. The Kennedy Fellows Program, at the City University of New York (CUNY) and the State University of New York (SUNY), seeks to address these service quality deterrents through a mentoring program.

Within the last two decades, mentoring has emerged as a positive means of enhancing learning and career development. The Kennedy Fellows program, which provides scholarships to New York college students who are also direct-care workers, offers such a mentoring program to its Fellows. The goal of this mentoring program is to support the higher education and career advancement of direct-care workers in the disabilities field. College faculty and provider agency professionals serve as role models, career sponsors, and academic advisors. The ongoing one-on-one mentoring process, as well as supportive peer relationships with other Fellows, is intended to encourage worker-students to achieve personal potential and move up the career ladder.

Mentors are expected to network for resources that their Fellows can use and to help Fellows network for themselves. While certain minimum expectations are set by the Kennedy Fellows Program for both the students and the mentors, the particular mentoring behavior is based on each student's needs.

For more information contact Lyda Clifton at (212) 794-5673.

## Universal Enhancement

*A staff training program on inclusion*

Area Served: National

Contact: Thomas Pomeranz, Chief Clinical Officer
VOCA Corporation
5555 Parkcenter Circle, Suite 200
Dublin, OH 43017
Phone (800) 837-8622, Ext 3273/Fax (614) 793-8584

---

VOCA Corporation, a service provider for people with developmental disabilities, uses a staff training program called "Universal Enhancement." The program teaches service provider staff the skills of inclusion and relationship building. Universal Enhancement promotes opportunities for individuals to experience social interactions of value and meaning. It opens inclusionary pathways that, historically, have been limited by attitudes, regulations, and funding mechanisms.

Through Universal Enhancement, staff members learn to listen, extend options for choice, role model, and design a prosthetic environment. Using a "circle of friends" approach, trainers ask trainees to complete a *Quality of Life Profile* on themselves. This approach assesses the relationship between valued activities in one's life and the extent to which these activities involve others. Trainers ask participants to think of a person with a disability and the number of people in that person's life. These people should not be relatives, paid staff, or other people with disabilities. Participants then identify the activities valued in the life of person with the disability. These exercises help trainees to recognize the barriers to inclusion that many environments build.

Universal Enhancement provides staff members with the tools to overcome constraints and limitations that prevent inclusion in highly regulated environments. These tools are uncomplicated and unconstrained. VOCA's Universal Enhancement program has resulted in a higher quality-of-life for the people served and the quality-of-working conditions for staff members. People with disabilities now engage in more choice and decision making. VOCA staff members now operate under the assumption of doing *with* people, versus doing *to* people. In turn, people who are served by VOCA are immersed in reciprocal giving. Many people served are community volunteers, or offer assistance to neighbors and co-workers.

For more information, and complimentary newsletter articles on Universal Enhancement, contact Thomas Pomeranz at 1-800-837-8622, Ext 3273.

# Kansans Educating and Empowering Persons with Developmental Disabilities

*A statewide training program for direct service staff*

Area Served: Kansas

Contact: Kathleen Olson, Community Training Coordinator
University Affiliated Program at Parsons
University of Kansas
2601 Gabriel, Box 738
Parsons, KS 67357
Phone (316) 421-6550, Ext. 1859/Fax (316) 421-6550, Ext. 1702

---

The skills and attitudes of direct service staff members are significant factors in the quality of services provided and the quality of life experienced by consumers. An accessible and affordable ongoing staff-training program becomes particularly important when relatively low salaries make it difficult to hire experienced and well-trained staff personnel.

In response, Kansas University Affiliated Program, has developed a statewide training program for direct service staff members. It is called "Kansans Educating and Empowering Persons with Developmental Disabilities." This program trains staff members to address such quality issues as personal health, functional assessment of behavior, skill development, personal choice, personal planning, community presence, and meaningful social relationships.

Because this project is statewide it has been necessary to train instructors from several agencies. In turn, the instructors have developed a training network to share training resources and innovative strategies. These relationships have promoted interagency collaboration among service providers which often result in a greater availability of course offerings.

The Kansas program uses a train-the-trainer model. It has a series of six instructional modules presented over 15 training sessions; optional college credits are available. Thirteen of Kansas's 19 community colleges now work with service providers to offer this curriculum to community-based direct service staff.

Success of the program is attributed to the development by the project of highly detailed training modules.

For more information about the program and the set of training modules contact Kathleen Olson at (316) 421-6550, Extension 1859.

## Program Status Review

*An internal review for service provider staff*

Area Served: Bentonville, Arkansas

Contact: Keith Vire, Executive Director
NW Arkansas Family Support Services
P.O. Box 697
Bentonville, AR 72712
Phone (800) 748-9768/Fax (501) 271-0819

---

In 1988, a group of families with the mission of keeping their children with disabilities at home incorporated themselves as Northwest Arkansas Family Support Services (NAFSS). Today, it continues to support families and individuals in their homes and communities with such services as supported living and supported employment. This agency is worth examining not only for its uniqueness, but also for its innovative and successful internal staff quality review process, Program Status Review (PSR).

This internal review process is designed and implemented by employees. In a supported living situation, for example, all staff members come together to formulate standards, guidelines, and training needs. These standards and guidelines reach beyond state minimum standards and reflect the goal of improving services. Staff members then use these guidelines to check their own performances. Additionally, cross checks are conducted by staff members of different NAFSS residential sites. From these checks weekly status reports are issued in clear and easy to understand terms.

The purpose of PSR is not to reprimand employees who do not meet standards but to open discussion on what can be done to achieve the standards that staff has established for its members. PSR has taken on a friendly competitive mode among employees that reflects the agency's overall competitive attitude to offer the best services.

PSR began in January 1992 to address problems from the rapid growth of NASS. It is viewed by many as having contributed to improved services, increased employee morale, and lower employee turnover.

For more information contact Keith Vire at (501) 273-0338.

## Leisure is for Everyone (Life Training)

*A training program for recreation service providers*

Area Served: Georgia

Contact: Lynn K. Poole
c/o Governor's Council on Developmental Disabilities
2 Peachtree Street, NW
Third Floor, Suite 210
Atlanta, GA 30303
Phone (404) 667-3007/Fax (404) 657-2132

---

The Georgia Governor's Council on Developmental Disabilities has developed Georgia LIFE (Leisure Is For Everyone) Training, to train recreation professionals to include persons with developmental disabilities in existing recreation programs and activities.

Modeled after a program at the University of North Carolina, Georgia LIFE adds information on the Americans with Disabilities Act. Training videos and other materials produced by the program assist those persons by program staff members to train others upon return to their own localities. Cited as key elements in the program's success are the support of the Georgia Parks and Recreation Association and the Governor's Council on Developmental Disabilities; availability of continuing education credits for trainees; a strong public relations effort; and the inclusion of persons with disabilities as members of the training staff.

The Governor's Council on Developmental Disabilities provides funding of $25,000 to Georgia LIFE Training. The program is managed through a contract with the consulting firm, Power Plus, Inc., headed by Ms. Lynn Poole. Ms. Poole expects to use Paralympic athletes and speakers who are involved in tennis, theater, water, and music programs in upcoming LIFE Training Workshops.

For more information on videos and other training materials phone the Georgia Governor's Council on Developmental Disabilities at (404) 657-2126. For information on the Georgia LIFE Training program phone Lynn Poole at (404) 667-3007.

## Story Writing

*A staff story writing program*

Area Served: Madison, Wisconsin

Contact: Gail Jacob, Executive Director
Options in Community Living
22 North Second Street
Madison, WI 53704
Phone (608) 249-1585/Fax (608) 249-3372

---

Connecting people to the meaning of their work enhances the quality of services at Options in Community Living where staff commitment is built through the practice of story writing. Staff members then share their stories at monthly staff meetings.

Story writers use their narratives to explore their thoughts and feelings about issues of importance to them in relation to their work at Options in Community Living. The stories are structured much like journal entries or personal letters. They provide glimpses of ongoing relationships and careers, and they encourage seeing which experiences are significant to staff members.

Options in Community Living staff members have found Story Writing to be a helpful way to discover meaning in their daily work, make sense of difficult situations, and raise hard questions. Story Writing also helps to strengthen staff relationships with the organization and one another. These stories communicate the challenges, frustrations, dilemmas, and rewards in serving people with developmental disabilities.

Staff members feel more connected and able to release stress as a result of these Story Writing experiences. Gail Jacob, Executive Director, says the quality of staff work at Options in Community Living has increased due to this unique program. She also attributes a new sense of organizational intimacy to Story Writing. Essential to the success of Story Writing has been the requirement that all staff members participate each month. Some members are nervous at first, but most come to enjoy writing and sharing their stories. Ms. Jacob feels that others embarking on similar programs should separate the program from other staff requirements.

*Remembering the Soul of Our Work*, a book of stories by Options in Community Living staff, and other information and materials are available by contacting Ms. Jacob at (608) 249-1585.

# Peer Review for Qualified Mental Retardation Professionals

*A QMRP training and internal review process*

Area Served: Louisiana

Contact: Sue Merrill, Program Manager
Division of Mental Retardation/Developmental Disabilities
1201 Capitol Access Road
P.O. Box 3117
Baton Rouge, LA 70821-3117
Phone (504) 342-0095/Fax (504) 342-1384

---

People with developmental disabilities who live in the community need competent persons to assist them with needed supports. The State of Louisiana Peer Review for Qualified Mental Retardation Professionals (QMRPs) is a strategy to provide a person-centered training, evaluation, and quality assurance tool for staff members to obtain such competency.

Through a clear definition of responsibilities and outcomes, the Peer Review guidelines provide a basis for QMRPs on how to do their jobs more effectively. Agencies use Peer Review guidelines to evaluate the strengths and weaknesses of QMRP performance. They are flexible enough to be used in any situation. They list some necessary elements that are present in any setting for the QMRPs to adequately perform their jobs. The guidelines are a training and internal review instrument, not another survey.

The accompanying Peer Review process takes place face-to-face by peer review teams. These teams consist of an out-of-state person, a facility QMRP, and a QMRP from another facility. Resulting from the Peer Review process is the development of action plans and technical assistance for the evaluated QMRPs. The goal of the Peer Review Process is to develop a system that can: (1) produce a common understanding of the roles and responsibilities of QMRPs; (2) focus on outcomes and not punishment; (3) upgrade residential facilities; and (4) improve service entities.

Peer Review began in February of 1991. The Division of Mental Retardation/Developmental Disabilities administers and funds the project at approximately $75,000 annually.

For more information on Peer Review for QMRPs "Best Practices Guidelines," packets, and other information contact Sue Merrill at (504) 342-0095.

## Integrated Training

*An early child care training program that focuses on disability issues*

Area Served: North Dakota

Contact: Helen Danielson, Director
North Dakota Early Childhood Training Center
North Dakota State University
P.O. Box 5057
Fargo, ND 58105
Phone (701) 231-8289/Fax (701) 231-7174

---

North Dakota's Integrated Training program is enhancing the quality of care for young children with disabilities. This module-based training program helps child care providers to become more comfortable with children with special needs to and educate child care providers on inclusion. The intended outcome of this program is to increase the number of child care providers for children with disabilities.

Integrated Training's modules are based on Child Development Associate credentials. Professionals conduct module workshops using an interactive style to get workshop attenders involved in the module topic. For example, module seven on creativity may have workshop participants creating machines in which people play the parts of the machine. Later, they are asked to adapt this activity for children with disabilities.

North Dakota child care staff members are not required to attend modules. Training, however, is free and continuing education units at North Dakota State University are available. Since the program's beginning in April 1992, attendance at training modules has steadily increased.

Integrated Training resulted from a shortage of child care providers for children with disabilities. The Americans with Disabilities Act, along with growing awareness of the absence of a systematic training approach, also influenced its development. Funding is provided for Integrated Training by the North Dakota Developmental Disabilities Council and North Dakota Human Services.

For copies of the training modules or more information contact Helen Danielson at (701) 231-8289.

# Minnesota Statewide Direct Service Training Initiative

*Training direct-care service staff*

Area Served: Minnesota

Contact: Amy Hewitt, Project Coordinator
University of Minnesota, Institute on Community Integration
214 Pattee Hall, 150 Pillsbury Drive S.E.
Minneapolis, MN 55455
Phone (612) 625-1098/Fax (612) 625-6619
Internet: hewit005@maroon.tc.umn.edu

---

The Minnesota Statewide Direct Service Training Initiative (MSDSTI) is a collaborative training effort among the Minnesota Technical College System, the Minnesota Governor's Council on Developmental Disabilities, and the University of Minnesota's Institute on Community Integration. This initiative has created an innovative, coordinated training program for direct service/paraprofessional staff, provider agencies, families and community resources throughout a primarily rural state.

Thirty-two technical colleges have joined the MSDSTI since its creation and over 1,800 direct service providers have received training. Some of the training sessions have reached expanded audiences through interactive television (ITV) broadcasts. Additionally, 92 trainers have attended train-the-trainer sessions designed to enhance capacity for quality training, both within the technical colleges and within provider agencies. Training offered through the technical colleges is priced at $29.00 per session. The Minnesota Governor's Council on Developmental Disabilities has funded scholarships for parents and consumers made available through Arc Minnesota. The MSDSTI also works to identify existing regional provider groups to share training resources and to collaborate on training events. Currently, thirteen such regional consortia exist, and more are being developed. These consortia include membership from provider agencies, technical colleges, parent/advocacy groups and self-advocacy groups.

The MSDSTI has published *A Guide to High Quality Direct Service Personnel Training Resources* (1994), a collection of evaluations of 100 training materials for direct care service providers, and is developing future editions which will soon be available world wide via the Internet. For topics on which limited curriculum exists, new materials are being created. Much of this new curriculum is in the form of multi-media interactive modules. The MSDSTI also publishes the quarterly newsletter for trainers of direct care workers, *Initiative*. Additionally, MSDSTI staff maintain a calendar of training events on an Internet (Gopher) server.

MSDSTI is funded by the Administration on Developmental Disabilities, the Minnesota Department of Human Services, and the Minnesota Governor's Council on Developmental Disabilities. However, many other organizations contribute to the success of MSDSTI.

For more information about the project or for materials, contact Amy Hewitt at (612) 625-1098. For information regarding training at the technical colleges, contact Jean Ness, Project Coordinator, Minnesota State Board of Technical Colleges, at (612) 626-9516.

# SCOUT

*Computer-Based, In-House Staff Training*

Area Served: Twin Cities, MN

Contact: Bob Niemiec, Director of Training
Kaposia, Inc.
380 East Lafayette Freeway South
St. Paul, MN 55107-1216
Phone (612) 224-6974/Fax (612) 224-7249

---

Kaposia, a supported employment company, is investing in the development and use of an interactive, computer-based staff training tool. The technology, called SCOUT, supplements Kaposia's in-person staff training. SCOUT is also used to track employee information.

SCOUT's training component takes the learner through Kaposia's service delivery process beginning with inquiries about Kaposia. The training includes 16 to 18 "stops," each corresponding to a different Kaposia aspect.

Kaposia and Knowledge Management, Inc. jointly developed SCOUT. The premise on which they built SCOUT was that experienced Kaposia staff members who leave Kaposia take their knowledge and expertise with them. Another factor was the large amount of time it took to orient new Kaposia employees. Third, Kaposia found that staff members need information at various times of the day or night. SCOUT allows employees to access information any time, accelerates the orientation process, and captures the collective knowledge of past and present employees.

SCOUT is still in its infancy. Recently, Kaposia installed SCOUT on Kaposia's computer network, and trained 18 employees on SCOUT's use. The response from staff members has been enthusiastic. Many trained staff members are actively using the system and providing critical feedback for improvement. As SCOUT grows and becomes comprehensive, Kaposia has plans to market SCOUT externally.

For more information from Kaposia contact Bob Niemiec at (612) 224-6974. To contact Knowledge Management call Larry Walker at (612) 851-9997.

# INNOVATIVE PRACTICES

## Advocacy Training and Support for Individuals and Families

## Partnership Fund

*A program that funds advocates and consumers to participate in events*

Area Served: Georgia

Contact: Harry Burkett, Community Relations Coordinator
Governor's Council on Developmental Disabilities
Third Floor, Suite 210
2 Peach Tree Street NE
Atlanta, GA 30303
Phone (404) 657-2126/Fax (404) 657-2132

---

The goal of the Partnership Fund (PF) is to encourage the inclusion of people with developmental disabilities and advocates in a wide range of events concerning developmental disabilities. An expected outcome of this funding is (1) the general empowerment of consumers and families, and (2) their involvement in planning and policy making. The ultimate goal is that consumers' inclusion will enhance the quality of services.

The PF provides a mechanism to support consumers' and families' participation in disability-related educational and policy-making events. It directly responds to the single most asked for assistance identified in public forums: information/training.

In 1994 the PF provided thirty awards to various disability support and advocacy groups across the state. PF's unique contribution is that all the funds are solely used to support the involvement and participation of people with disabilities and their families; there are no administrative fees, staff costs or other hidden costs. Additionally, PF is consumer driven in that the "what and how" is decided by those using the funds. The PF has directly supported 594 self-advocates and family members to attend various disability-related educational and policy-making events. The events supported were primarily in Georgia, but out-of-state events were also supported. In all cases participants were supported in collecting and sharing information directly with people in their advocacy/support group and other interested parties.

The Partnership Fund began in May 1992. The Governor's Council on Developmental Disabilities and organizations that sponsor events provide financial support for the Partnership Fund.

For more information or to receive *The Partnership Fund Packet*, contact Harry Burkett at (404) 657-2126.

# Parent Case Management

*An empowerment and training program*

Area Served: Minnesota

Contact: Marijo McBride, Coordinator, Parent Case Management Program
Institute on Community Integration, University of Minnesota
150 Pillsbury Drive S.E., 103 Pattee Hall
Minneapolis, MN 55455
Phone (612) 624-6830/Fax (612) 624-9344

---

The goal of the Parent Case Management Program is to reach persons with disabilities, parents, and guardians to participate more fully in the management of services. Parent Case Management promotes empowerment through training and technical assistance. A key element in the training is knowledge of rules, systems, and resources.

This program began in 1986 with the training of parents and in 1992 moved into training facilitators to bring the ideas of Parent Case Management to communities. The program provides support for both parents and facilitators who are now out in their communities conducting training and technical assistance. Facilitator training includes a one-day session covering state-of-the-art philosophy in case management issues for persons with developmental disabilities, plus resources and skills to implement the Parent Case Management Program. Training includes implementation of the program on both a one-to-one and group presentation basis. Trainees receive a resource guide, facilitator's guide, handouts, and a newsletter subscription. The program also provides facilitators with technical assistance for implementing the program and a $100 stipend.

Parent Case Management for People of Color is a program within Parent Case Management. Similar to Parent Case Management, it is committed to creating flexible family support that builds on the unique capacities of families. Collaborating with leaders in the African-American and Native American communities and community organizations, the program seeks to be an effective and culturally sensitive tool for the empowerment of individuals with disabilities and their families.

Marijo McBride says consumers are demonstrating their empowerment in the use of the service system a year and more after Parent Case Management training. She attributes the success of the program to the support of key players through technical assistance, networking, training, and the availability of a stipend.

Parent Case Management has been funded through the Minnesota Governor's Planning Council on Developmental Disabilities and the Institute on Community Integration, which also manages and supports the program. The Parent Case Management for People of Color is funded in part by the National Institute on Disability and Rehabilitation Research. It is an adaptation of the Minnesota Arc Suburban Parent Case Management program, and The Orange County California Regions Services Center's Parent Coordinator Program.

For more information or materials contact Marijo McBride at (612) 624-6830.

## Partners in Policymaking

*An empowerment and training program*

Area Served: Minnesota

Contact: Colleen Wieck, Executive Director
Minnesota Governor's Planning Council on
Developmental Disabilities
300 Centennial Office Building
658 Cedar Street
St. Paul, MN 55155
Phone (612) 296-4018/Fax (612)297-7200

---

To achieve true quality assurance, consumers of services and their families need knowledge, skills, and opportunities to effectively express their needs and concerns. Partners in Policymaking was developed in Minnesota in 1987 by the Governor's Planning Council on Developmental Disabilities (DD Council) as a way to develop new leadership, provide intensive training, and build a shared vision throughout the state. Over 200 individuals are graduates of Minnesota's Partners in Policymaking and the program has been replicated in 25 states.

Partners in Policymaking trains consumers and their families in state-of-the-art practices and services and gives them the knowledge and skills needed for influencing policy makers. Graduates of this training become actively involved in promoting quality through advocacy for themselves and their families and through participation in public activities. These advocacy efforts focus on such areas as personal choice, personal planning, community presence, employment, supported living, education, family support, and technology.

Since 1991, Minnesota Partners in Policymaking graduates have been involved in a longitudinal study. Quantitative data collected showed that over 90% of Partners in Policymaking graduates were able to secure better services as a result of their participation in this community leadership program. A majority of graduates used skills acquired through the Partners in Policymaking experience to influence public officials. A majority also had the opportunity to educate the public about the rights and needs of persons with disabilities.

Qualitative data show that graduates rate Partners in Policymaking as an excellent, worthwhile, and invaluable training program. Graduates also rated their ability to secure appropriate services as good or excellent. Partners in Policymaking gives consumers and their families the knowledge, skills, and insight to recognize when and where change is necessary; the tools to clearly and factually present information to policy makers; and the confidence to effectively advocate for positive systems change.

The information on Partners in Policymaking includes a manual, recruitment brochures, and curriculum materials. Minnesota DD Council staff members urge people to call them about the program directly at (612) 296-4018.

## Community Resource Teams

*A rural model for the empowerment of communities*

Area Served: Alaska

Contact: Roy Scheller, Deputy Director
Supported Family Living Services
Hope Cottages, Inc.
540 West International Airport Road
Anchorage, AK 99518
Phone (907) 561-5335 ext. 431/Fax (907) 564-7429

---

The formulation of Community Resource Teams (CRTs) meaningfully involves consumers, parents, and advocates in designing, implementing, and assuring quality of supports. These teams act as community hubs to produce community owned supports responsive to unique rural needs.

CRTs grew out of a group of parents from the rural town of Dillingham, with the desires to get services in their community. Formerly, those with disabilities had go to metropolitan areas to receive services.

Concerned people such as parents, teachers and Alaskan Native leaders now compose CRTs. These teams act as advisory councils to Hope Cottages, Inc., a nonprofit private provider of services to people with developmental disabilities. They also solicit local support, act as connections to their communities and advocates, address problems, and provide for networking and informal education about the service system. CRTs are instrumental in accessing state funding for respite care, case management, and family support.

Robin Ynacay-Nye, Director, Supported Family Living Services for Hope Cottages, says it is important for those working with such teams to remember that team members must be taken seriously and need tangible, results-oriented projects in order to stay focused. For more information contact Roy Scheller at (907) 561-5335 ext., 431.

## Pueblo Developmental Disabilities/Mental Health Consortium

*A consortium that seeks to prevent incarceration or institutionalization of people*

Area Served: Colorado

Contact: Larry Velasco, Executive Director
Pueblo County Board for Developmental Disabilities, Inc.
115 West Second
Pueblo, CO 81003
Phone (719) 546-0572/Fax (719) 546-0577

---

In the absence of an inclusive, integrated system of planning and services, persons with the dual diagnosis of mental retardation and mental illness are often denied appropriate and necessary services. The same is true of many individuals with mental retardation who are criminal offenders.

In 1987 the Pueblo County Board for Developmental Disabilities, in partnership with a number of other community agencies, and with funding from the University Affiliated Program at Colorado University, began the Pueblo Developmental Disabilities/Mental Health Consortium. A voluntary organization without special funding, the Consortium is made up of community leaders in human services, the justice system, vocational rehabilitation, and other agencies. Consortium members seek to prevent the incarceration or institutionalization of persons with developmental disabilities and either mental illness or involvement in the criminal justice system. Consortium members provide these people with opportunities to live in the community with necessary supervision, treatment, and supports.

Hiring a consultant; arranging a visit to Pueblo by staff members from a Pennsylvania project similar to the Consortium; and supporting Consortium members' attendance at professional meetings are a few examples of the project's ongoing efforts to benefit from the experiences and expertise of other people. In addition to planning and implementing services for persons within the target population, the Consortium has directed and coordinated special resources across traditional programmatic barriers to the benefit of individuals who require more than a single program can offer. Critical steps in developing this program were defined as (1) developing a thorough knowledge of the community; (2) identifying and enlisting key community leaders; and (3) nurturing respect and trust among Consortium members. A training manual has been developed by the Developmental Disabilities/ Mental Health Consortium and is available at minimal cost.

For the manual or further information contact Larry Velasco at (719) 546-0572.

# Neighborhood Living Project

*A research, training, and demonstration project*

Area Served: Oregon

Contact: Steve Newton, Assistant Professor/Research Associate
Neighborhood Living Project
Specialized Training Program
1235 University of Oregon
Eugene, OR 97403-1235
Phone (503) 346-2470/Fax (503) 346-5517

---

The mission of the Neighborhood Living Project (NLP) is to improve the lives of transition-age youth and other individuals with severe intellectual disabilities who live in community residences. NLP's current research is focused in two areas: enhancing the social relationships of individuals with severe intellectual disabilities by improving their social networks, social integration, social support, and stability of social relationships; and facilitating and honoring the preferences of individuals with severe intellectual disabilities.

Since 1981, NLP has helped over 300 residential providers to implement the Valued Outcomes Information System (VOIS). VOIS ensures that residential services are planned, provided, and internally evaluated based on the service outcomes valued by participants and their families. VOIS also provides information on the degree to which the valued outcomes are experienced by participants. Providers use this information to improve the congruence between the lifestyles preferred by participants and the lifestyles they actually lead.

NLP is a project within the Specialized Training Program, a research and development unit within the Division of Special Education and Rehabilitation at the University of Oregon's College of Education. The U.S. Department of Education's Office of Special Education Programs; the National Institute on Disability, Rehabilitation and Research; and Oregon's Office of Developmental Disability Services fund NLP. NLP began in response to a request from the U.S. Department of Education for projects to develop, implement, evaluate, and communicate about models for achieving deinstitutionalization and community integration of children and youth with severe handicaps in normalized, nonsegregated environments.

For a complete list of materials and more information contact Steve Newton at (503) 346-2470.

## Atlanta Alliance on Developmental Disabilities Family Support Services

*Provides and accesses services for persons with disabilities*

Area Served: Fulton and Dekalb counties, GA

Contact: Lana Copeland Hardy, Director
Family Support Services (formerly Project: RESCUE)
Atlanta Alliance on Developmental Disabilities
215 Lakewood Way SW, Suite 105
Atlanta, GA 30315
Phone (404) 622-5343/Fax (404) 622-6575

---

Providing quality service to people regardless of income level, sex, or parental status is a challenge to the disabilities field. Atlanta Alliance on Developmental Disabilities (AADD) is meeting this challenge by assessing the needs of and providing services for people with little money, including single mothers with mental retardation.

AADD functions primarily to connect people to resources through direct personal contact and assistance. Case coordination is provided for all consumers. Each person and family is looked at individually. Goals range from providing assistance with budgeting to increasing community connections. Supported employment and residential services are also provided when necessary.

AADD is a private, nonprofit agency contracting with the Department of Human Resources to provide family support services. State and Federal grants, United Way funds, and private money provide funding. Annual costs are approximately $800,000.

Mary Yoder, Assistant Executive Director, AADD, feels the program has been successful because it has aided consumers in being reunited with their families, owning their own homes, and getting jobs in the community. She sees challenges for consumers in limited housing for people with little money and other challenges of poverty.

For more information contact Lana Copeland Hardy at (404) 622-5343.

# Family Support Advisory Councils

*Volunteer regional councils that assure quality*

Area Served: Louisiana

Contact: Sandee Winchell, Assistant Director
Governor's Council on Developmental Disabilities
PO Box 3455
Baton Rouge, LA 70821
Phone (504) 342-0437

---

Louisiana has legislated quality assurance methods for its Community and Family Support System which include regional and state Advisory Councils. Currently these Family Support Advisory Councils look at quality and implementation issues for the cash subsidies from the Family Support Program component of the system. However, plans are in place to expand the focus of these councils to other services within the Family Support Program as expansion funds are secured.

Formed in Fall 1992, these councils have begun to help with outreach, documentation, and implementation issues. Since Council members are themselves parents of children with disabilities, the councils provide for networking and advice for parents learning to access services. A three hour training and orientation program has been developed to assist the Councils in their work.

Issues that are statewide in nature are brought by regional councils to the state Family Support Advisory Council. Although the Councils have no formal authority, both state and regional Advisory Councils do bring issues to light and provide assistance.

Recently two parents were hired part-time as liaisons between the Councils and the Community and Family Support System Task Force, which oversees and implements the entire Community and Family Support System Plan. Council seats, however, are unpaid volunteer positions.

For more information contact Sandee Winchell at (504) 342-0437.

## Community Capital Housing Project

*A program that assists people to rent or own their own homes*

Area Served: Ohio

Contact: Jennifer Johnson
Ohio Department of Mental Retardation/Developmental Disabilities
35 East Chestnut Street, 5th Floor
Columbus, OH 43215
Phone (614) 644-9084/Fax (614) 644-6676

---

Persons with developmental disabilities may enjoy opportunities to exercise control of their own homes through Ohio's Capital Housing Project (CHP). Since 1989, CHP has assisted Ohioans with developmental disabilities to rent, and sometimes own, their own homes. Mandated independence of housing agencies from residential service providers, with separation of housing and services expenditures, enables consumers to change service providers while remaining in their homes.

The Ohio Department of Mental Retardation and Developmental Disabilities (ODMR/DD) manages the program, which is funded by the sale of municipal bonds. Participating counties select and contract with non-profit corporations to purchase and manage the houses for a fixed fee; the state MR/DD agency provides or guarantees mortgage funding on a case-by-case basis. Residents with developmental disabilities typically pay rent, maintenance, and operating costs with Supplemental Security Income (SSI) or other income. When the mortgage is fully paid, ownership may, in certain cases, be transferred to the residents of the home.

The program continues to expand. It now provides typical housing for over 800 persons with developmental disabilities in Ohio. More than $7 million is budgeted for this program biennially.

For additional information, including a written summary of the program, contact Jennifer Johnson at (614) 644-9084.

## Residential Development

*A regional process that provides consumer choice of service providers*

Area Served: Connecticut DMR Region 5

Contact: Tom Meehan, Director of Community Services
DMR Region Five
104 South Turnpike Road
Wallingford, CT 06492
Phone (203) 294-5043/Fax (203) 294-0220

---

It is a common belief that allowing people with developmental disabilities to choose who will provide them with services creates the kind of competition that is essential to improving service quality. Connecticut Department of Mental Retardation, Region Five (Region 5) has been testing this belief by offering people with developmental disabilities entering into supported living arrangements the opportunity to select among provider agencies.

Region 5 began implementing Residential Development in 1992 with 19 people who were seeking supported living arrangements. These people were profiled with the aid of their case managers and the profiles were distributed to area provider agencies at a regional conference. Provider agencies that desired to serve particular individuals so indicated to Region 5, and Region 5 then distributed to consumers profiles of the provider agencies seeking to serve them. Consumers and their families thereupon set about examining and interviewing the potential agencies and selected the one that best met their needs.

Some difficulty in time delays and confusion was experienced by the consumers. Overall, however, the families and consumers found the process to be positive, and Region 5 has seen a decrease in the number of consumers complaints.

Tom Meehan noted that provider agencies are promising an increased level of service during the interview process and, therefore, must follow through with these promises to meet consumer expectations. The additional costs to Region 5, he noted, have been minimal.

For more information call Tom Meehan at (203) 294-5043.

## "Parents are Experts" Parents Training Parents

*Parental advocacy training, information, referral, and support*

Area Served: Wayne, Oakland, & Macomb counties, MI

Contact: Barbara Cardinal, Associate Executive Director
United Cerebral Palsy Association of Metropolitan Detroit, Inc.
23077 Greenfield, Suite 205
Southfield, MI 48075-3745
Phone (810) 557-5070/Fax (810) 557-4456

---

United Cerebral Palsy Association of Metropolitan Detroit (UCP) is a parent and consumer advocacy organization for persons with cerebral palsy and other disabilities, and their families. Through a variety of UCP programs and services, choice and control of services have become a reality to many persons with disabilities in Wayne, Oakland, and Macomb counties in Michigan.

As part of UCP, the "Parents are Experts" Parents Training Parents (PTP) program was established in 1983 through a grant from the U.S. Department of Education. PTP is based on the idea that parents are experts about their children. This program provides skill training and information to assist parents and family members to understand and deal with systems and resources that are critical in their children's lives. The program provides direct training and services to over 1,400 parents each year.

PTP offers a variety of training for parents and professionals on relevant federal and state laws. Training covers how to: prepare for Individual Education Planning committee meetings, communicate with special educators and service professionals, increase self-esteem and parent power, and become advocates. In addition, PTP trains parents to become Parent Trainers who provide support and service as a resource to other parents.

The project recognizes that no one is more concerned, and better able to advocate for the educational well-being of children than informed parents. PTP has strong participation from multiracial and ethnic groups, non-English speaking parents, and parents who have disabilities. All training is done in native languages, and takes place in accessible settings that are close to the participant's communities.

For brochures and information about the project and other services of United Cerebral Palsy contact (810) 557-5057.

# New Hampshire Self Determination Project

*A project that links self-determination with individual consumer budgets*

Area Served: New Hampshire

Contact: Tom Nerney
Mondadnock Developmental Services
640 Marlboro Street, Route 101
Keene, NH 03431
Phone (603) 352-1304/Fax (603) 352-1637

---

The New Hampshire Self Determination Project is a three-year demonstration project with the goals of (1) increasing the quality of life for consumers participating in the project and (2) decreasing per capita spending for services. Through the project, personal networks are to replace professionally dominated service teams in assisting consumers. The role of the case manager will be transformed to a personal agent who serves as a catalyst to help the consumer realize and define a positive future.

The project has three major parts:

(1) each consumer will be given the opportunity to control planning for their needs with the assistance only of those people they choose;

(2) each consumer will be given a budget of Medicaid and state money, which they may spend on residential, employment, and personal needs as they, and those persons they choose to assist them, determine; and

(3) services for the consumer will be purchased through a variety of brokering methods, and each consumer will be free to purchase any services through separate contracts.

A premise of the project is that linking self-determination with individual consumer budgets will result in lower costs and more satisfactory outcomes for consumers. Early data suggest some per capita savings and enhanced quality of life for consumers.

For more information contact Tom Nerney at (603) 352-1304.

# Project PILOT (People Integrating and Learning Outdoors Together)

*Empowering and training persons with disabilities*

Contact: Greg Lais, Executive Director or
Nancy Simmet, Program Director for Training
Wilderness Inquiry
1313 5th Street S.E., Box 84
Minneapolis, MN 55414
Phone (612) 379-3858/Fax (612) 379-5972

---

Project PILOT has a primary goal of training and empowering people with disabilities to assertively and positively influence their environments. As a result of participation it is expected that Project PILOT participants, all of whom have disabilities, will demand and help develop better services, especially in outdoor recreation settings. Managed by Wilderness Inquiry (WI), a nonprofit outdoor adventure organization, Project PILOT trains persons with disabilities to be integration specialists. These integration specialists then provide accessibility and integration information to outdoor recreation service providers. The project has also opened new employment markets for person with disabilities, through skill training, introductions to prospective employers, and volunteer opportunities in which participants receive important work experience.

Thirty persons with disabilities participate per year. Project participation includes:

- twenty-one hours of integration training,
- planning and presenting integration outdoor skills workshops,
- reviewing information for organizations requesting assistance in making their program accessible,
- outdoor adventure traveling through WI's regular travel program,
- establishing a network of integration specialists, and
- twenty hours of volunteer community and outdoor recreation activities.

Some participants are also involved in Universal Program Training. In this capacity participants will work with agencies such as the U.S. Forest Service and the National Park Service to train outdoor recreation professionals on accessibility, integration, and disability issues.

Project PILOT participants represent an array of disabilities. Participants currently receive or must be eligible for services from a state Department of Rehabilitation Services. Project PILOT is funded by the U.S. Department of Education.

Outcomes for Project PILOT participants have ranged widely. Some become active volunteers and advocates within their communities. Others have found careers within agencies that provide recreation services and that serve people with disabilities. For more information contact Nancy Simmet at (612) 379-3858.

# INNOVATIVE PRACTICES

## Best Practices

## Best Practices Forums

*A forum to communicate quality practices*

Area Served: Arizona

Contact: Cathy Sweeney or Jamie Blamer
Department of Economic Security
Division of Developmental Disabilities
Quality Advocacy Unit
P.O. Box 13178
Tucson, AZ 85732
Phone (602) 628-6800/Fax (602) 628-6809

---

A place for open exchange among stakeholders of ideas, theories, and opinions on concerning developmental disabilities is provided through the Best Practices Forums.

These regional forums are held four times a year in a neutral environment, such as a public library. A panel facilitates the two to four-hour long forums. 50 to 75 people ask questions and offer comments to the panel. A provider focus group sets forum agendas. Ideas for forums usually come forward when a provider has a successful practice to be shared. The tone of the forums, therefore, is positive.

The goals of these forums are to communicate ideas and to plant seeds for quality practices in the developmental disabilities field. Additionally, the forums bring together people who hold different perspectives. In many cases this has resulted in participants gaining new insight and empathy for opposing views.

Best Practices Forums began in January 1992 as an outgrowth of provider focus groups. Arizona's Department of Economic Security loosely manages the forums, which operates without direct funding. However, the Department is considering ways to give participants, particularly parents and consumers, per diem pay for attendance at forums.

For more information, contact Cathy Sweeney or Jamie Blamer at (602) 628-6800.

# Nekton Best Practices Manual

*Forums and manuals of innovative practices initiated by staff*

Area Served: Minnesota

Contact: Peter (Skip) Sajevic, President
Nekton, Inc.
One Griggs Midway
1821 University Avenue
St. Paul, MN 55104-2800
Phone (612) 644-7680/Fax (612) 643-6777

---

Developing mechanisms for sharing creative ideas to resolve problems and improve services is vital in assuring quality in services for people with developmental disabilities. Affirming direct service staff members for their creative activities and commitments is also important to their professional development and tenure. Nekton, Inc. does this through agency best practices forums and dissemination of a best practices manual.

The forums on best practices are an established agency program, held as part of all-agency staff meetings. The manual identifies examples of best practices in supporting someone with developmental disabilities in individual opportunities, achievements, and accomplishments. Nekton compiles these descriptions of best practices into a best practices manual and shares them among all agency staff. The manual is an anecdotal guide to creative practices that focus on serving people, not the agency.

Submissions have varied in their complexity, scope, and focus. One example described a process that aided an individual in joining a church choir. The successful practice eventually lead to the staff member withdrawing from the activity, as community members began aiding the individual in getting to choir practices.

For a copy of Nekton's *Best Practice Manual* or additional information contact Skip Sajevic at (612) 644-7680. The fee of $5.25 covers printing and postage charges.

# Pennsylvania Search for Quality Practices in Early Intervention

*A process to recognize quality early intervention practices in Pennsylvania*

Area Served: Pennsylvania

Contact: Susan Maude, Project Coordinator
The Early Learning Institute
2500 Baldwick Road, Suite 15
Pittsburgh, PA 15205-4144
Phone (412) 937-3093/Fax (412) 937-7960

---

The Pennsylvania Department of Education, with the Department of Public Welfare, annually conducts a search for quality practices in the area of early intervention for all infants, toddlers and preschoolers with developmental delays and their families. The purpose is to recognize quality service delivery programs in early intervention, and to provide models for other community programs. Staff members from the recognized programs must be available to provide technical assistance.

Each year requests for applications are sent to public and private programs throughout the Commonwealth. Applications are reviewed by panels of parents and early intervention experts. The panel members then select programs for on-site visits which teams of parents and professionals conduct. The final review committee of parents and Department representatives selects the community programs to be honored at an annual statewide early intervention conference. Honorees present their quality practices in workshops at an annual conference.

Information about finalists is reported in the *Pennsylvania Early Intervention* newsletter, a statewide newsletter with distribution of 8,000. This information is also published in the monograph *Quality Practices in Early Intervention in Pennsylvania: Evaluation and Case Studies*.

For more information or a copy of the monograph contact Susan Maude at (414) 937-3093. To receive the newsletter, contact Pennsylvania's Office of Mental Retardation at (717) 787-3700.

# INNOVATIVE PRACTICES

## Quality Assurance in Community Supported Living Arrangements Programs (CSLA)

# Quality Assurance in Community Supported Living Arrangements Programs

Medicaid Home and Community Based Services (HCBS) waiver programs exist in 50 states to provide services in community and family homes to persons with developmental disabilities who might otherwise be placed in ICFs-MR or nursing homes. While offering states an attractive alternative to institutional care, states have long sought greater flexibility to experiment with services and clearer opportunities to serve individuals with developmental disabilities, irrespective of their being "at risk" of institutional placement. Advocates of increased self-determination for state persons with developmental disabilities, including many state officials, have also sought a more specific value-base focus on people having greater control over their own lives and support services.

In 1990 Congress added Section 1930 to the Social Security Act to allow eight states to provide Community Supported Living Arrangements (CSLA) to Medicaid-eligible persons with developmental disabilities for a five-year period. In many ways similar to the Medicaid HCBS waiver programs, the CSLA program provided states with greater flexibility in service provision and permitted specific targeting of services to new eligibility groups and to specific geographic areas within a state. Unlike the Medicaid HCBS waiver CSLA did not require that ICF-MR or nursing home level-of-care need be established for eligibility. In a manner much more specific than the Medicaid HCBS waiver, but still permitting a high degree of state flexibility and control, CSLA required each state to develop its own quality assurance program within areas defined by federal standards.

The eight states selected to provide CSLA (California, Colorado, Florida, Illinois, Maryland, Michigan, Rhode Island and Wisconsin) varied in their target populations, projected numbers of recipients, services to be included and other factors. However, the states shared a common perception of the CSLA option as an opportunity to serve in new ways, unserved, underserved or inadequately served groups of persons with developmental disabilities. The CSLA program expected participating states to enhance quality of services by integrating a number of elements of quality assurance which consumers, advocates, providers and other professionals argued would contribute to more effective quality assurance and enhancement. These expectations, especially the creation of "Community Monitoring Boards," created expectations in the area of quality assurance that went considerably beyond those of the Medicaid HCBS program.

On September 30, 1995 the five year authorization of Medicaid CSLA ends. States are currently in the process of either converting their present CSLA programs into special supported living waiver programs, integrating the present CSLA program into an existing waiver program, or redesigning their existing waiver programs to accommodate CSLA principles, as well as to continue supports to current CSLA participants.

As states explore alternative mechanisms to accommodate the end of CSLA, the nature and extent of their continuation of CSLA quality assurance programs will vary. In future updates of this sourcebook the directions taken by states in quality assurance will be provided. The following pages outline the approaches being taken to quality assurance in the state CSLA programs as they complete the final year of the CSLA experiment.

# Quality Assurance for CSLA-California

Area Served: California

Contact: Julia Mullen
Adult and Supported Living Services
Department of Developmental Services
1600 9th Street
Sacramento, CA 95814
Phone (916) 654-2426/Fax (916) 654-3641

---

California's Community Supported Living Arrangements (CSLA) program is designed to be highly consumer centered in its approach to quality assurance and enhancement. In addition to the more traditional efforts by state, regional, and local authorities to positively affect service quality through periodic inspection and review, California has incorporated three significant new elements into its CSLA program.

The Consumer Bill of Rights is central to planning, providing and monitoring CSLA services to Californians with developmental disabilities. It assures consumers the right to choice, dignity, respect, success, involvement in development of their Individual Service Plans, and the power to say "No" in matters affecting their lives. Assurances include maximum consumer control of the use of CSLA dollars, including the right of individual consumers to "hire and fire" their direct service providers and provider agencies.

Area Boards, funded by the Developmental Disabilities Council, operate Community Monitoring Teams (CMT) in each state region that participate in CSLA to survey the satisfaction and quality of life of individual consumers. One Area Board contracts with a citizen advocacy agency to act as a CMT. More typically, CMTs are organized by Area Boards using a "friendship model." Area Boards encourage CMT involvement in various ways through such activities as surveys of consumers' families and friends to find CMT volunteers, and sponsorship of social mixers for consumers and team members, with individual consumers choosing CMT members from persons they come to know.

Each consumer develops from the community a Circle of Support, an informal personal support network. Members of an individual network may perform various functions that respond to the consumer's needs and preferences, including helping to develop the consumer's Individual Service Plans, engaging in leisure activities with the consumer, and becoming a trained advocate for the consumer.

For additional information and CSLA program materials contact Julia Mullen at (916) 654-2426.

# Quality Assurance for CSLA-Maryland

Area Served: Maryland

Contact: Hal Franklin, Assistant Director
Statewide Programs
Developmental Disabilities Administration
Department of Health and Mental Hygiene
201 West Preston Street, Fourth Floor
Baltimore, MD 21201
Phone (410) 225-5600/Fax (410) 225-5850

---

Health, safety, choice, empowerment, community integration, and consumer happiness are the primary aspects of daily living targeted by Maryland's CSLA quality assurance program. Maryland approaches quality assurance in these areas through a variety of methods.

A cornerstone of Maryland's quality assurance approaches are the CSLA consumer empowerment rights. Examples are the right to terminate the provider agency and the right to review and revise the Individual Service Plan (ISP) at any time and for any reason. Friends and family of the consumer also may call for an ISP review at any time.

Maryland's Quality Assurance Review Committees (QARCs) are a primary mechanism for monitoring individuals' quality of life and service. Consumers, consumers' friends and families, and CSLA providers make up these committees. Some committees focus on people served by a single provider while others may focus on people served by several provider agencies. Teams of committee members visit each consumer at least twice a year. Team members are nominated by individual consumers; they attend to the services specifically provided to individuals and assess consumer satisfaction with services, health and safety. Members reports to the general QARC which distributes reports to relevant parties, including providers--who must respond to suggestions for change--as well as to regional and state agencies.

An Advisory Committee made up of persons from various constituencies, also has been developed to advise Maryland's Developmental Disabilities Administration (DDA) staff of CSLA program quality. This committee is autonomous from DDA, has no formal power, and is intentionally designed to be informal and advisory in nature.

Hal Franklin may be contacted for more information at (410) 225-5600.

# Quality Assurance for CSLA-Michigan

Area Served: Michigan

Contact: Judy Webb
Office of Federal Liaison and Entitlements
Department of Mental Health
Sixth Floor, Lewis Cass Building
320 South Walnut
Lansing, MI 48913
Phone (517) 335-4078/Fax (517) 335-6775

---

Quality in Michigan's CSLA approach is dependent upon the presence and effectiveness of the following six dimensions: Person-Centered Planning; Consumer Choice and Control; Health and Safety Accommodations; Easy Access to Complaint Resolution; Consumer Satisfaction Feedback; and Training of Communities, Service Providers, Families and Consumers.

Through person-centered planning, consumers, and people who know consumer well, identify the quality parameters and desired outcomes of the supports to be provided. Any accommodations to assure health and safety, or needs for the training providers, family members, and/or consumers, are discussed during this process. At least annually, this planning group discusses the degree to which the outcomes have been achieved. However, the ongoing involvement of the consumer's friends and family are found to be the most effective informal monitors of the supports being provided. Likewise, choice of, and control over providers by the CSLA consumer has impacted how providers view and treat consumers.

Quality is formally measured by the consumer twice a year through the *Consumer Satisfaction Assessment* which is administered by a local volunteer community monitoring board. Consumers choose the format for this assessment as well as the person(s) to assist them in the process. Information from the two-page questionnaire is aggregated, analyzed, and then shared with local authorities, as well as state authorities in order to make revisions in service delivery functions. In addition, consumers meet with case managers quarterly, at which time they discuss how the program is impacting the individuals' lives. Finally, consumers have access to a complaint process that addresses simple criticisms and formal grievances. Quality is also formally monitored by the State through annual on-site surveys of the CSLA administering agencies, and their subcontracts.

Judy Webb, Department of Mental Health, feels an important aspect of Michigan's CSLA program is that it is locally driven and flexible. She expects to see programs develop that are unique to their local areas.

For more information contact Judy Webb at (517) 335-4078.

# Quality Assurance for CSLA-Rhode Island

Area Served: Rhode Island

Contact: Sue Babin, Administrator
Division of Developmental Disabilities
Department of Mental Health, Mental Retardation, and Hospitals
600 New London Avenue
Cranston, RI 02920
Phone (401) 464-3234/Fax (401) 464-3570

---

Rhode Island's plan to assure and enhance quality in its Community Supported Living Arrangements (CSLA) program involves efforts by a variety of organizations and individuals including the state Division of Developmental Disabilities (DDD), the state Developmental Disabilities Council, Consumer/Parent Monitoring Boards, CSLA provider agencies, and consumers themselves. The state Division of Developmental Disabilities has developed a Quality Assurance Manual addressing human rights, service outcomes, and minimum assurances. DDD makes unannounced visits to CSLA programs, conducts annual quality assessment reviews and provides technical assistance to CSLA providers. The DDD also disseminates an annual family satisfaction questionnaire for families to provide comments on their perceptions of the impact of CSLA on the life of their family member.

The state Developmental Disabilities Council has contracted with an outside agency to conduct annual evaluations to determine the effectiveness of CSLA services as an alternative to traditional service systems and to measure consumer satisfaction. Three Consumer/Parent Monitoring Boards evaluate the involvement in decision making, and satisfaction with supports received, of each CSLA consumer within their respective regions. Consumer/Parent Monitoring Board activities are closely tied to the Individual Support Plan review process.

The state CSLA Advisory Committee meets at least bi-monthly and is composed of persons initially brought together to design the CSLA application, with the intended benefit of optimizing information and dissemination about CSLA in Rhode Island. CSLA quality assurance in Rhode Island is funded by state and federal agencies and with a $15,000 training and consultation grant from the state and Developmental Planning Council.

For more information contact Sue Babin at (401) 464-3234.

# Quality Assurance for CSLA-Wisconsin

Area Served: Wisconsin

Contact: Tom Swant, CSLA Coordinator
Bureau of Developmental Disabilities Services
Division of Community Services
Wisconsin Department of Health and Human Services
1 West Wilson Street, P.O. Box 7851
Madison, WI 53707
Phone (608) 266-3717/Fax (608) 266-0036

---

Wisconsin's goal for its CSLA quality assurance program is to emphasize monitoring responsibility by local governments, while providing less direct state monitoring and more state technical assistance. Given the relatively high level of county control over services in Wisconsin, this provides for a better integration of quality assessment, service development, and service authorization.

The state certifies counties as CSLA service provider agencies and surveys them annually. Counties in turn certify providers. State staff members visit consumers and families to assure health and safety, contacting at least twenty-five percent of all program participants. Wisconsin uses a review process which includes examining consumer empowerment and quality-of-life issues. In 1994, the state began using a guardian questionnaire to find out guardian satisfaction regarding residential supports, vocational/day services, case management and health issues. Most of those responding have been very satisfied with CSLA supports.

Case managers also provide ongoing monitoring of services and individual well-being. In Wisconsin, case management does not necessarily need to be conducted by a professional. Consumers are free to choose an unpaid family member to coordinate services. The state, however, still assigns a professional case manager to act as a government contact person and consultant to the consumers. In addition, local monitoring boards conduct site visits and consumer interviews to assess consumer satisfaction with CSLA services and report findings annually to the state Bureau of Developmental Disabilities Services. The state prepares an annual report summarizing the findings of local monitoring boards.

For more information contact Tom Swant at (608) 266-3717.

# Quality Assurance for CSLA-Florida

Area Served: Florida

Contact: Linda Davis, Director, Supported Living Project
Department of Health and Rehabilitation Services
1317 Winewood Boulevard, Building 5, Room 210
Tallahassee, FL 32301
Phone (904) 488-4257/Fax (904) 922-6456

---

In Florida, a four part quality assurance and quality enhancement system is being established for supported living services in Florida, including those provided through CSLA.

First, support coordinators (case managers) aid consumers in choosing among service providers and make a home visit to consumers each quarter. The purpose of the visit is to check on the individual's health and well-being, review his or her need for financial assistance through state general revenue funds, and ensure that the individual is receiving supports and services as authorized by the support plan. The supported living coach participates in this meeting if the individual has no objection. Support coordinators are also required to make at least monthly telephone contacts with consumers.

Second, district developmental services program offices conduct annual unannounced visits to supported living coaching providers to monitor compliance with certification requirements and all applicable laws and regulations. If providers are out of compliance, district offices will require providers to develop a plan of corrective action. Suspension or termination of provider certification can be imposed for continuing deficits.

Third, consumers are asked to complete annual surveys that examine their satisfaction with supported living services received and whether these services are helping the person move toward individualized outcomes. If the individual needs or wants assistance in completing the survey, friends, family, or neighbors may be asked to help. Paid staff providing direct supported living services to an individual may not be part of the survey activities for that individual. Survey results are forwarded to the district developmental services program office which is responsible for ensuring that appropriate follow-up occurs. Survey results will also be sent to the state supported living monitoring board.

A supported living monitoring board is being established and will have at least one representative from each of the following groups: individuals in supported living, supported living service providers, family members of individuals in supported living, and friends or neighbors of individuals in supported living. The board will address service outcomes as determined through individual survey activities and issue an annual report that addresses issues and trends in services and includes recommendations.

For materials or other information regarding supported living or CSLA in Florida contact Linda Davis at (904) 488-4257.

# Quality Assurance for CSLA-Illinois

Area Served: Illinois

Contact: Connie Sims
Bureau of Policy, Planning and Program Development
Illinois Department of Mental Health & Developmental Disabilities
419 William Stratton Building, Room 419
Springfield, IL 62765
Phone (217) 524-2515/Fax (217) 782-9535

---

Statewide systems of independent service coordination and volunteer monitoring are central to the process of assuring and enhancing service quality in Illinois' Community Supported Living Arrangements (CSLA) program. In addition, a statewide oversight board provides input and makes recommendations regarding the CSLA program.

Independent service coordinators are a recent innovation on a statewide basis in Illinois. Under this system, activities often performed by case managers in other states are the responsibility of independent service coordinators in Illinois. Independent service coordinators are employed by private agencies that may not provide, or be related to agencies that provide, other services to persons with developmental disabilities.

The state experimented with the creation of a statewide network of trained volunteer CSLA advocates, coordinated in each of three areas in late 1994. A report concluded that 90% of the respondents were satisfied with their living arrangements. Illinois may extend the volunteer advocate project to other program areas in the future.

Illinois has published a user-friendly consumer handbook and a technical assistance guide for both consumers and service providers.

For materials and further information contact Connie Sims at (217) 524-2515.

# Quality Assurance for CSLA-Colorado

Area Served: Colorado

Contact: Heidi Cunningham, Program Manager
*Program Quality*
Division for Developmental Disabilities
3824 West Princeton Circle
Denver, CO 80236
Phone (303) 762-4581/Fax (303) 762-4300

---

Colorado has designed a multifaceted approach to quality assurance for CSLA that distributes responsibility for quality assurance among many stakeholders. Provider agencies, monitoring boards, Community Centered Boards, and the Division for Developmental Disabilities conduct various quality assurance activities that intentionally overlap.

Colorado's CSLA program is currently in its third year with 13 of its 20 Community Centered Boards (CCBs) providing CSLA. These nonprofit local boards contract with the state of Colorado to provide or purchase services for individuals with developmental disabilities in their geographic service area. Local monitoring boards have been set up under CCBs providing CSLA to review CCB practices in monitoring health and well-being of participants, review CSLA minimum protection compliance, evaluate agency practices in resolving consumer complaints, assess consumer satisfaction with services, review the extent to which consumers are offered real choices and assisted to make increasingly responsible decisions. Monitoring boards are required to meet at least quarterly, survey agencies at least annually, and hold open forums annually.

The Division developed *A Training Manual for Monitoring Boards* to give board members an overview of CSLA, their responsibilities, and suggestions for ways to fulfill those responsibilities. This manual also includes information on organizing volunteer boards. Recently, the Division additionally sponsored training sessions/meetings. Among the topics covered were "What Makes People Safe" and a review of actual situations where people have been placed at risk and responses to these situations.

The Division also conducts agency reviews annually, and within 90 days of agency CSLA approval. The Division finds that CSLA flexibility is resulting in creative individual plans and that consumers are particularly pleased with increased control over their own services. Other sources of CSLA quality assurance in Colorado are: case management monthly monitoring; provider agency individualized monitoring plans; and a systematic evaluation of the CSLA program that will be conducted within the first two years.

For more information or materials contact Heidi Cunningham at (303) 762-4581.

# INNOVATIVE PRACTICES

## Networking

## Positive Approach Committee

*Creating networks to promote positive behavioral approaches*

Area Served: Pennsylvania

Contact: Nancy Thaler, Director
Bureau of Community Programs
Office of Mental Retardation
Department of Public Welfare
PO Box 2675
Harrisburg, PA 17105-2675
Phone (717) 787-3700/Fax (717) 787-6583

---

Recent advances in our understanding of human behavior have caused professionals to rethink the behavioral management approach of control over persons with developmental disabilities. Instead, understanding behavior as communication leads to finding ways to the need for challenging behavior.

This shift in thinking and interventions requires a change in the attitude of care givers. To support a change in attitude, the culture in which they work must change.

In response, the Pennsylvania Office of Mental Retardation gathered a group of professionals who championed positive behavioral strategies into a statewide Positive Approaches Committee. This committee, made up exclusively of volunteers, has designed and provided training conferences, developed policy guidelines, provided consultation across the state, and modeled the benefits of sharing expertise and supporting each other. The committee has also spawned the development of regional positive approaches networking groups. These networks provide a system of peer support for consumers, direct care staff and agency administrators who want to make change. The networks confirm their belief in the benefits of listening to people and supporting them.

The statewide Positive Approaches Committee has initiated a spin-off network group for those employing facilitated communication. This facilitated communication network group provides training and has also developed extensive guidelines for the use of facilitated communication in Pennsylvania, another spin-off from the positive approaches networks.

The networking has reached other systems. In the Fall of 1994, the Positive Approaches Committee co-sponsored a two-day conference with the Pennsylvania Department of Education and the State Office of Mental Health. Over 1,600 people participated at the conference through teleconference downlink sites.

For additional information contact Nancy Thaler at (717) 787-3700.

## Family Support Network

*An information, referral, advocacy, and network service*

Area Served: Greater Fall River Area, Massachusetts

Contact: Jeanne Vincent, Network Coordinator
Adsum, Inc.
105 Bank Street, PO Box 1511
Fall River, MA 02722
Phone (508) 678-6550/Fax (508) 677-9239

---

Education and information are important ways to enhance quality in services. Family Support Network works to strengthen education and information for families of children with developmental disabilities in southeastern Massachusetts. The Network provides referral to and information on various resources of potential assistance to families on both a local and statewide basis. It also provides educational advocacy, family assessment, and a resource library; and it works through its network to create needed services for families for whom services are currently unavailable.

The idea for Family Support Network came from people with developmental disabilities who receive supported living services from Adsum, Inc., a private nonprofit organization. These adult consumers of services suggested that a referral and information service might help to keep children out of institutions. Adsum responded by applying for and receiving a grant from the Massachusetts Department of Mental Retardation in 1988. This grant offers funding that allows Family Support Network to provide services to families without charging fees.

Over 200 families have used the services of Family Support Network. Many of these families have shown their gratification by volunteering for projects and referring other families to Family Support Network. An evaluation survey of families has shown them pleased with the partnership concept that supports parents in taking on leadership roles in their children's lives. Many families, however, expressed a desire for connecting to recreational activities for their children; Family Support Network is actively addressing such connections.

Family Support Network is managed by Adsum and operated by Adsum staff and volunteers. For more information contact Jeanne Vincent at (508) 678-6550.

# INNOVATIVE PRACTICES

## Accreditation

# Outcome-Based Performance Measures

*A guide to measuring service outcomes*

Area Served: United States

Contact: James Gardner, Chief Executive Officer
Accreditation Council on Services for People with Disabilities
8100 Professional Place, Suite 204
Landover, MD 20785-2225
Phone (301) 459/Fax (301) 577-0703

---

Accreditation Council on Services for People with Disabilities developed *Outcome-Based Performance Measures* to shift the definition and assessment of quality in-services from provider inputs and processes to measurements of consumer outcomes. This change in focus reflects the belief that consumer satisfaction and quality of life are the best indicators of the quality of services a person receives.

The *Outcome-Based Performance Measures* instrument is designed to be administered to consumers on an individual basis. Its 30 items examine such areas as personal goals, choice, relationships, dignity and respect, health, security, satisfaction, environment, and social inclusion. The items were selected using individual and focus group interviews to identify priority outcomes which people with disabilities indicated to be most important to them. The Council field-tested the *Outcome-Based Performance Measures* for validity and reliability and continues to conduct validity and reliability tests as part of its national accreditation program quality reviews. *Outcome-Based Performance Measures* is used to engage in activities responsive to the individual consumer; to conduct self-assessment by service provider agencies of their organization's effectiveness in supporting consumers in achieving their desired outcomes; and to conduct independent quality reviews of service provider agencies.

The Council has completed accreditation reviews with several organizations across the United States using the new *Outcome-Based Performance Measures*. The review process is resulting in "recommendations that are more specific and practical." The Council plans to test new ways to involve people with disabilities, parents, staff, and community members in the review process.

To purchase a copy of *Outcome-Based Performance Measures* or to request additional information, phone the Council at (301) 459-3191.

# CARF Accreditation

Area Served: United States and Canada

Contact: Ken Groggel, Director of Operations
Employment and Community Supports Division
101 North Wilmot Road, Suite 500
Tucson, AZ 85711
Phone (502) 748-1212/Fax (502) 571-1601

---

One of the many mission related purposes CARF has articulated is "to provide an independent, impartial, and objective system of total organizational review and assessment using a peer review approach." To this end CARF has developed a set of standards titled *1995 Standards Manual and Interpretive Guidelines for Employment and Community Support (Standards),* and a protocol for CARF accreditation.

These standards define the expected inputs, processes, and outcomes of services for people with disabilities. CARF gathers National Advisory Committees each year to review standards sections. Committee recommendations are sent for review to consumers, accreditation organizations, surveyors, professional groups, purchasers of services, and many more.

To receive CARF accreditation, an organization can expect to:

1. Conduct a CARF self-evaluation and prepare to demonstrate the results.

2. Receive a CARF 2-day site visit, during which consumers, staff members, and purchasers of services will be interviewed; activities will be observed; and documents will be reviewed by peers in the field.

3. Receive a CARF report of strengths and areas of weakness to which the organization must respond and make suggestions for improvement strategies.

The 1995 CARF Standards reflect a move toward expectations of person-centered and outcome-based services for persons with disabilities. Standards now include sections on individual-centered planning, service design and delivery; along with consumer satisfaction and service outcomes. Within the program specific sections of the standards CARF is gradually introducing person-centered and outcome based concepts. The Community Supports Standards section includes standards which focus on individually tailored supports, consumer choice, and positive outcomes for consumers. The proposed 1996 CARF Standards currently being reviewed, includes person-centered standards for Employment, Early Childhood and Family Supports, and Cash Management.

For more information contact Ken Groggel at (502) 748-1212.

# APPENDIX A

## Quality and Disability Related Publications

*Lack of space prevents the inclusion here of the many publications and video tapes produced by the projects profiled in this source book. For such materials, contact the persons listed at the top of each profile.*

## Standards and Measurements

**A Checklist for Evaluating Personal Assistance Services (PAS) Policies and Programs**. O'Brien, C. L., & O'Brien, J. (1992).

This checklist is a tool to help people describe what is missing in currently available programs and to communicate changes that are necessary .

Available from the Research and Training Center on Community Integration, Center on Human Policy, School of Education, Syracuse University, 200 Huntington Hall, Syracuse, NY 13244-2340, phone (315) 443-3457, fax (315) 443-4338.

**Final Report on Quality Assurance Assessment Instruments**. Allen, Shea, & Associates. (1993).

The Colorado Division of Developmental Disabilities contracted with Allen, Shea, and Associates to review 72 measurement instruments in quality assurance measurement as part of Colorado's Program Assessment and Review (COPAR). This sourcebook presents profiles of both COPAR and Allen, Shea, and Associates' Final Report (see COPAR and Quality Measurement Instrument Review).

Available from Allen, Shea, and Associates for approximately $9.95. Contact them at: 1040 Main Street, Suite 200B, Napa, CA 94559, phone (707) 258-1326.

**Outcome Based Performance Measures**. Accreditation Council on Services for People with Disabilities. (1993).

The Accreditation Council's manual describes 30 outcomes identified by people with disabilities and forms the Accreditation Council's quality enhancement and accreditation program. A profile in an earlier part of this book depicts the Outcome Based Performance Measures (See ACD-Outcome Based Performance Measures).

Available from the Accreditation Council on Services for People with Disabilities, 8100 Professional Place, Suite 204, Landover, MD 20785-2225, phone (301) 459-3191, fax (301) 577-0703.

**Quality Assurance Resources: Instruments, Organizations, and Publications**. Wieck, C., Nelson, J., Reedstrom, C., Starr, J., & Stone, N. (1989).

This book describes and provides ordering information for quality assurance instruments, organizations, and publications for monitoring services.

Available from the Research and Training Center on Community Integration, Center on Human Policy, School of Education, Syracuse University, 200 Huntington Hall, Syracuse, NY 13244-2340, phone (315) 443-3457, fax (315) 443-4338.

**Quality of Life: Its Measurement and Use.** In *Mental Retardation*, 27, 25-31. Schalock, R., Keith, K., & Hoffman, K. (1989).

This article proposes a quality-of-life index that may be used either as an outcome measure or as a criterion for the goodness-of-fit between people and their environments.

Available from AAMR, 444 North Capitol Street, NW, Suite 846, Washington, DC 20001, phone (800) 424-3688, fax (202) 387-2193.

**Signs of Quality: Words to Serve By**. People on the Go. (1992).

This booklet contains ideas for self-advocates so that they can decide how good a service is.

Available from People on the Go, Arc/Maryland, Suite 310, 6810 Deer Path Road, Baltimore, MD 21227, phone (410) 379-0400.

**1995 Standards Manual and Interpretive Guidelines for Employment and Community Support.** CARF. (1995).

This manual outlines CARF standards and interpretive guidelines to these standards. The standards are the basis of CARF accreditation for organization that serve people with disabilities. The 1995 version now shows the interpretive guidelines on the same page as the standards, which makes the manual easier to use. The 1995 version also reflects CARF's move toward including person-centered and outcome-based standards in CARF's accreditation process.

Available from CARF, 101 North Wilmot Road, Suite 500, Tucson, AZ 85711-3335, phone (602) 748-1212, fax (602) 571-1601.

**Symposium on Compliance and Quality in Residential Life.** In *Mental Retardation*, 30 (3). Rowitz, L. (Ed.). (1992).

This issue of *Mental Retardation* is devoted to discussing the search for balance between protections that bureaucratic regulations attempt to provide for people with mental retardation, and the efforts to support them. Writings and commentaries are included by Senator Edward Kennedy, James Gardner, Elizabeth Boggs, Steve Taylor, and others.

Available from AAMR, 444 North Capitol Street, NW, Suite 846, Washington, DC 20001, phone (800) 424-3688, fax (202) 387-2193.

# Quality Management

**Continuous Quality Improvement in Oregon's Programs for People with Developmental Disabilities**. Brodsky, M., & Wilson, D. (1992).

This source book describes the application of total quality management approaches to small programs for persons with developmental disabilities. It follows the quality philosophy of W. Edwards Deming, and uses a seven-step system for developing and implementing an improvement plan. This sourcebook also contains a profile of Oregon's statewide program (See profile "Oregon System of Continuous Quality Improvement").

Available from Paradigm Systems, P.O. Box 967, Salem, OR 97308-0967, phone (503) 363-8609.

**The Deming Management Method.** Walton, M. (1988).

The Deming Management Method reviews the work of W. Edwards Deming, quality management consultant, with emphasis on his Fourteen Points. It also profiles the quality methods of various organizations that have implemented Deming's techniques. It is an excellent book upon which readers can build knowledge of organizational quality concepts.

Available at local and college book stores.

**Quality Improvement in Employment and Other Services: Managing for Quality Through Change.** Albin, J.M. (1992).

This book is written for the staffs of agencies that provide supported employment for people with severe disabilities. It is relevant, however, to a wide range of service provider agencies. Its focus is how to apply quality improvement approaches developed in business to services for people with severe disabilities who live in communities.

Available from Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285.

**Quality Is Free: The Art of Making Quality Certain.** Crosby, P. (1980).

The author discusses methods he considers practical, productive, and cost effective in managing and improving quality. He takes a long-term quality focus, and stresses that monitoring for problems after-the-fact is more costly than developing quality systems up front. Crosby's book includes his Fourteen-Step Quality Improvement Program and his Quality Management Maturity Grid.

Available from Penguin Books USA, 375 Hudson Street, New York, NY 10014 or at local book stores.

**Reinventing Government: How the Entrepreneurial Spirit is Transforming the Public Sector.** Osborne, D., & Gaebler, T. (1993).

The authors outline an approach to cutting taxes, improving public services, and moving away from bureaucracy. It includes profiles of existing entrepreneurial governments and the ten principles on which the authors consider the government to be constructed.

Available from Penguin Books USA, 375 Hudson Street, New York, NY 10014, or at local book stores.

**Total Quality Management: A Paradigm for the '90s. Total Quality Management for Mental Health and Mental Retardation Services.** Sluyter, G., & Mukherjee, A. (1993).

The book describes the application of total quality management for organizations that provide services for people with disabilities. It leads the reader through the processes and practices developed by W. Edwards Deming, and depicts how they may be applied to human services.

Available from ANCOR, 4200 Evergreen Lane, #315, Annandale, VA 22003, phone (703) 642-6614, fax (703) 642-0497.

# Advocacy

*Many of the publications in this section do not list a publication date or author, as the organization making the publication available did not have, or would not release the information.*

**Aids to Advocacy for Developmentally Disabled Persons: A Bibliography and Resource Guide.** Developmental Disabled Protection and Advocacy System.

This guide provides a list of books, booklets, conference proceedings, newsletters, articles, and audio-visual resources that give information on advocacy.

Available from Arc/Minnesota, 3225 Lyndale Avenue South, Minneapolis, MN 55408, phone (800) 582-5256 or (612) 827-5641.

**The Americans with Disabilities Act.** U.S. Department of Justice.

This booklet discusses the effects of the Americans with Disabilities Act on employment, public accommodations, transportation, state and local government operations, and telecommunications relay services.

Available from Civil Rights Division, U.S. Department of Justice, P.O. Box 66118, Washington, D.C. 20035, phone (202) 514-0301.

**A Handbook for People Thinking about Moving.** People First of Washington.

This workbook helps self-advocates make informed choices about where they want to live. It also provides suggestions for people helping self-advocates.

Available from People First of Washington, P.O. Box 648, Clarkson, WA 99403, phone (509) 758-1123.

**Making Your Case. Minnesota Governor's Planning Council on Developmental Disabilities**. (1994).

This short book offers advocates for persons with disabilities and self-advocates techniques, tips, and insights to assist in lobbying efforts.

Available from the Minnesota Bookstore, 117 University Avenue, Main Floor, St. Paul, MN 55155, phone (612) 297-3000.

**Neighbors Helping Neighbors**.National Rural Independent Living Network.

This manual tells you how to start independent living networks for self-advocates in rural communities.

Available from National Rural Independent Living Network, School of Education, Western Washington University, Bellingham, WA 98225, phone (206) 676-3314.

**Rights and Responsibilities.** People First of California.

This fact sheet lists rights and responsibilities of self-advocates.

Available form People First of California, P.O. Box 3969, Chico, CA 95927-3969, phone (916) 899-7305.

**Self-Advocacy Groups: 1994-95 Directory for North America**. Institute on Community Integration. (1995).

This source guide lists over 700 self-advocacy groups across North America who offer support and empowerment to people with developmental disabilities.

Available from Publications Office, Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, phone (612) 624-4512, fax (612) 624-9344.

**Transportation**. Administration on Developmental Disabilities.

This fact sheet address how transportation is affected by the ADA. Topics include what types of transportation vehicles and facilities must be accessible and what things public transportation systems must do to accommodate people with disabilities.

Available from the Administration on Developmental Disabilities, Hubert H. Humphrey Building-Room 351-D, 200 Independence Avenue SW, Washington, DC 20201, phone (202) 690-6590, fax 690-6904.

**Your Rights Under the Rehabilitation Act of 1973**. South Carolina Protection and Advocacy System for the Handicapped. (1990).

This fact sheet provides information on the Rehabilitation Act of 1973. It explains who is covered by this law, who must obey this law, and gives examples of violations of this law.

Available from SCP&A System for the Handicapped, Inc., 3710 Landmark Drive, Suite 208, Columbia, SC 29204, phone (803) 782-0639.

# Quality Enhancement and Developmental Disabilities

**Creating a Conceptual Revolution in Community and Disability.** Schwartz, D. (1992).

In this book the author discusses the dilemmas surrounding funding decisions and quality assurance issues that result. The discussion is based on the author's experience as the director of the Pennsylvania Developmental Disabilities Planning Council.

Available from the Research and Training Center on Community Integration, Center on Human Policy, School of Education, Syracuse University, 200 Huntington Hall, Syracuse, NY 13244-2340, phone (315) 443-3457, fax (315) 443-4338.

**Legal and Ethical Dilemmas in Services for Persons with Mental Disabilities**. Sundram, C. Editor. (1995).

This monograph includes writings on the legal and ethical dilemmas faced in services for persons with mental disabilities. Contributing authors include Richard Surles, Michael Kennedy, Charles Schwartz, Elizabeth Chura and Nancy Ray.

Available from the New York State Commission on Quality of Care, 99 Washington Avenue, Suite 1002, Albany, NY 12210-2895, phone (518) 473-6302.

**The National Reform Agenda and People with Mental Retardation: Putting People First.** U.S. Department of Health and Human Services. (1994).

This manual contains the proceedings from the President's Committee on Mental Retardation's 1994 special forum. The publication contains addresses by President Clinton, committee members, and leaders from various fields, along with committee workgroups reports. Areas of focus include health care, welfare, long-term care, housing, education, employment, and financing.

Available from The U.S. Department of Health and Human Services, Administration for Children and Families, President's Committee on Mental Retardation, Wilbur J. Sohen Building-Room 5325, 330 Independence Ave, SW, Washington, DC 20201, phone (202) 619-0634, fax (202) 205-9519.

**The Paradox of Regulations: A Commentary**. In *Mental Retardation*, 30(3), 185-190. Taylor, S. (1992).

This article highlights the relationships between regulations and quality of life. The author points out that while regulations can act as safeguards against abuse, regulations are shown to thwart the potential for quality services.

Available from AAMR, 444 North Capitol Street, NW, Suite 846, Washington, DC 20001-1512, phone (800) 424-3688, fax (202) 387-2193.

**Report to the President. The National Reform Agenda and Citizens with Mental Retardation: A Journey of Renewal for All Americans.** Fujiura, G. (1994).

This report summarizes the research and opinions of participants at the Presidential Forum "The President's Reform Agenda and People with Mental Retardation - 21st Century Realities." It reflects the contributions of self-advocates, parents, and family members who collaborated with professionals and government staff members to evaluate the needs of Americans with mental retardation. Narratives and recommendations are provided in the areas of education, housing, employment, health, welfare, and long-term care.

Available from The U.S. Department of Health and Human Services, Administration for Children and Families, President's Committee on Mental Retardation, Wilbur J. Sohen Building-Room 5325, 330 Independence Ave, SW, Washington, DC 20201, phone (202) 619-0634, fax (202) 205-9519.

**Quality Assurance in an Era of Consumer Empowerment and Choice.** In *Mental Retardation*, 32(5), 371-374, Sundram, C. (1994).

This article discusses the author's seven key challenges to assuring quality in services for people with disabilities. Underlying the discussion is the author's advocacy for a common sense approach to providing services.

Available from AAMR, 444 North Capitol Street, NW, Suite 846, Washington, DC 20001-1512, phone (800) 424-3688, fax (202) 387-2193.

**Quality of Care, Quality of Life: A Rural Perspective.** In *Mental Retardation*, 32(5), 374-376, Heinlein, K. (1994).

This article focuses on the state of Wyoming's multi-method approach to quality of care. In the article the author discusses both macro and micro quality-of-life issues. He also presents some of the challenges for a service system within a large rural state.

Available from AAMR, 444 North Capitol Street, NW, Suite 846, Washington, DC 20001-1512, phone (800) 424-3688, fax (202) 387-2193.

**Safeguards**. In the Center on Human Policy's *Policy Bulletin* no. 3, Winter 1993.

This entire bulletin is dedicated to the question "what can we count on to make and keep people safe?" Various authors examine the need to increase people's safety by both strengthening community ties and providing more relevant assistance to people. Much of the discussions focus on reducing regulatory excess and encouraging quality in services for persons with developmental disabilities.

Available from AAMR, 444 North Capitol Street, NW, Suite 846, Washington, DC 20001-1512, phone (800) 424-3688, fax (202) 387-2193.

**Simple Solutions**. Oklahoma Advocates Involved in Monitoring (OK-AIM). (1995).

This pamphlet includes suggestions from OK-AIM volunteers of ways to improve the quality of life for individuals with disabilities. It presents practical easy-to-implement tips on consumer choice, privacy, communicating with persons who are nonverbal, building neighborhood relationships, and other topics.

Available from Tulsa ARC, 1601 South Main, Suite 300, Tulsa, OK 74119-4465.

**Quality Assurance for Individuals with Developmental Disabilities: It's Everybody's Business.** Bradley, V., & Bersani, H., Jr. (1990).

More than two dozen experts discuss quality assurance for persons with developmental disabilities in this book. Contributors include consumers, families, advocates, government personnel, academics, and others.

Available from Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624.

**Quality Assurance.** In *IMPACT*. 6(2). Lakin, K.C., Prouty, R., Smith, G. (Eds.). (Summer, 1993).

This entire issue of the quarterly journal *IMPACT* is devoted to the topic of quality assurance. It offers perspectives on innovative efforts to enhance service quality by such leaders as Clarence J. Sundram, Georgia Baddley, Jim Gardner, Kathleen Olson, and others.

A complimentary issue is available from Publications Office, Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, phone (612) 624-4512, fax (612) 624-9344 .

**Quality of Life: Perspectives and Issues.** Schalock, R. (1990).

Twenty-two contributors to Quality of Life offer chapters on various aspects of quality of life for people with mental retardation and developmental disabilities. The chapters are divided into four sections: personal perspectives; service delivery; assessment and measurement; and the future of quality of life concepts.

Available from AAMR Publication Center, P.O. Box 25, Annapolis, MD 20701, phone (301) 604-1340.

**What Can We Count On to Make and Keep People Safe?** O'Brien, J., Lyle O'Brien, C., & Schwartz, D. (Eds.). (1990).

*What can we count on to make and keep people safe?* contains excerpts of discussions and writings by participants in the Pennsylvania Developmental Disabilities Planning Council 1990 annual retreat. The report contains perspectives on creating effective safeguards for people with developmental disabilities. The personal security approaches of administrative regulations and legal advocacy are contrasted with lifesharing and other personal commitments.

Available from the Pennsylvania Developmental Planning Council, 569 Forum Building, Harrisburg, PA 17101, phone (717) 787-6057.

# Best Practices

**Best Practices**. Brodsky, M., & Wilson, D. (1992).

This manual provides brief descriptions of exemplary practices that support people with developmental disabilities in Oregon. It contains a description of this manual and its development (See Best Practices in Oregon).

Available from Paradigm Systems, P.O. Box 967, Salem, OR 97308-0967, phone (503) 363-8609.

**Best Practices Manual.** Nekton, Inc. (1993).

Nekton, a private provider of services for people with developmental disabilities, created this brief manual. It includes stories about successful outcomes, and processes to facilitate these outcomes, for people with developmental disabilities. The manual places emphasis on individuals with disabilities rather than the organization. Stories depicted in the manual are both inspirational and informative. This manual also contains a profile of this project (See Nekton Best Practices Manual).

Available from Nekton, One Griggs Midway, 1821 University Avenue, St. Paul, MN 55104-2800, phone (612) 644-7680.

**Exemplary Programs for Persons with Disabilities in Transition, Supported Employment, and Parent Professional Collaboration.** Institute on Community Integration. (1994).

This resource guide profiles 30 exemplary programs serving people with disabilities in Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin.

Available from Publications Office, Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, phone (612) 624-4512, fax (612) 624-9344.

**Whatever it Takes: Examples of Excellence in Family Support**. Human Services Research Institute. (1994).

This publication illustrates how family support provider agencies and programs have developed progressive family support practices. It contains examples of programs that respect family choices, make flexible supports available, and help families access the supports they need.

Available from the Human Services Research Institute, 525 Glen Creek Road N., #230, Salem, OR 97304, phone (503) 362-5682.

# Staff Development

**A Guide to High Quality Direct Service Personnel Training Resources.** Hewitt, A., Larson, S., & Lakin, K. (1994).

The Research and Training Center on Residential Services and Community Living has published a resource guide that identifies and evaluates direct service staff training materials. Trainers of community direct service personnel working in community homes may find this sourcebook useful.

Available from Publications Office, Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, phone (612) 624-4512, fax (612) 624-9344.

**Direct Service Staff Training.** In *IMPACT* 5(1) Wallace, T., Larson, S., & Hewitt, A. (Eds.). (Spring, 1992).

This issue discusses direct-care staff training, training delivery systems, training improvement models, and implications of various training approaches. Articles on the training of direct-service personnel in residential, vocational and educational settings are included, as are articles sharing the views of parents, consumers, and direct-care staff members.

Available from Publications Office, Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, phone (612) 624-4512, fax (612) 624-9344.

**Remembering the Soul of Our Work.** O'Brien, J., & Lyle O'Brien, C. (Eds.). (1992).

Options in Community Living, a provider of services for people with developmental disabilities in Madison, WI, presents the products of a staff storytelling project. (See profile "Story Writing").

Available from Options in Community Living, 22 North Second Street, Madison, WI 53704, phone (608) 249-1585.

**Framework for Accomplishment.** O'Brien, J., & Lyle O'Brien, C. (1987).

*Framework for Accomplishment* brings staff members through active self-evaluation and problem solving by focusing on the life preferences and desires of individuals served by their organization. The focus is to elevate the understanding and appreciation of individuals and to use available resources to improve the organization's contributions to lifestyles desired by persons served.

Available from Responsive Systems Associates, 58 Willowick Drive, Lithonia, GA 30038, phone (404) 987-9785.

**Developing Staff Competencies for Supporting People with Developmental Disabilities.** Gardner, J., & Chapman, M. (1993).

This publication presents a basic course in self-guided instruction and self-evaluation in the concepts, attitudes and knowledge of value in assisting persons with developmental disabilities in community settings. Staff members and others who provide services to persons with developmental disabilities may find this book a useful orientation.

Available from Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624.

# Community Living/Supported Employment

**Challenges for a Service System in Transition: Ensuring Quality Community Experiences for Persons with Developmental Disabilities.** Hayden, M., & Abery, B. (Eds.). (1994).

Numerous contributors to this book, including Charlie Lakin, Sheryl Larson, Robert Bruininks, and others, critically examine issues, research, and policies surrounding full community inclusion of individuals with developmental disabilities. The entire book is a useful guide for empowering people with disabilities and ensuring the quality of services that support them.

Available from Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624.

**Crossing The River: Creating Conceptual Revolution in Community and Disability.** Schwartz, D. (1992).

In Crossing the River, David Schwartz discusses the conception of rediscovering the importance for all people of being and feeling embedded in a web of personal relationships. He points out the promise, potential and limits of this new direction, illustrated through a series of experiments in social policy connected with the Pennsylvania Developmental Disabilities Planning Council.

Available from Citizen Advocacy Forum, P.O. Box 86, Beaver, PA 15009, phone (412) 775-4121.

**Down Stairs that are Never Our Own: Supporting People with Developmental Disabilities in Their Own Home.** In *Mental Retardation*, 32(1), 1-6. O'Brien, J. (1994).

In this article the author addresses choosing and controlling one's home environment as it relates to quality-of-life issues.

Available from the AAMR, 444 North Capitol Street, NW, Suite 846, Washington, DC 20001, phone (800) 424-3688, fax (202) 387-2193.

Also available through Responsive Systems Associates, 58 Willowick Drive, Lithonia, GA 30038, phone (404) 987-9785.

**Economics, Industry, and Disability: A Look Ahead.** Kiernan, W., and Schlock, R. (Eds.). (1989).

The contents of this book address the opportunities, challenges, and economic changes surrounding the supported employment movement for people with disabilities.

Available from Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624.

**The Employer's Pocket Guide to Supporting Workers with Disabilities: Valuing What Each of Us Brings to Our Work**. Training Resource Network, Inc. (1994).

This booklet expresses to employers the benefit of hiring people with disabilities and discusses how to support each employee to be as effective as possible. It additionally contains a summary of staff diversity in business.

Available from Training Resource Network, Inc., P.O. Box 439, St. Augustine, FL 32085, phone (905) 823-9800.

**Friends: A Manual for Connecting Persons with Disabilities and Community Members**. Amado, A.N., Conklin, F., & Wells, J. (1990).

This manual discusses strategies and methods for connecting persons with disabilities to people in the community. Topics include: planning, relationships, introducing people, continuing support, assisting others, agency support, and includes a list of resources.

Available from the MN Governor's Planning Council on DD, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155, phone (612) 296-4018.

**Housing, Support, and Community.** Racino, J., Walker, P., O'Connor, S., & Taylor, S. (Eds.). (1993).

This is volume two of the Community Participation series developed through the Center on Human Policy. It highlights efforts in communities to improve the quality of life for people with disabilities. It presents current strategies and unique ways of thinking about supporting people to live in their own homes and participate in their communities.

Available from Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624.

**Supported Living: New Directions in Services to People with Developmental Disabilities.** Smith, G. (1990).

This report describes emerging trends in supported living for persons with developmental disabilities including the goals, definitions of quality, and activities in various states.

Available from NADDDS, 113 Oronoco Street, Alexandria, VA 22314, phone (703) 683-4202, fax (703) 684-1395.

**Supported Living (Volumes 1 And 2).** National Association for Private Residential Resources (now ANCOR) (Eds.). (1991).

The readings and bibliographies in these volumes relate to supported living for people with developmental disabilities. They focus on the search for understanding, establishing, and maintaining quality of life as defined by individuals receiving supported living services. Contributors to Supported Living include John O'Brien, Jane Wells, Jay Klein, and others.

Available from ANCOR, 4200 Evergreen Lane, #315, Annandale, VA 22003, phone (703) 642-6614, fax (703) 434-6402.

**Supporting People with Severe Reputations in the Community.** Smull, M., & Harrison, S. (1992).

This handbook discusses ways to support people with disabilities and severe reputations in the community.

Available from NADDDS, 113 Oronoco Street, Alexandria, VA 22314, phone (703) 683-4202, fax (703) 684-1395.

## Health and Safety

**Destructive Behavior in Developmental Disabilities: Diagnosis and Treatment.** Thompson, T., & Gray, D. (1994).

This book provides professionals and researchers with an analysis of destructive behavior that goes beyond single-factor theories. The authors demonstrate how attention to the interaction of multiple variables can bring about solutions to complex behavioral problems.

Available from SAGE Publications, Inc., 2455 Teller Road, Thousand Oaks, CA 91320, phone (805) 499-9774.

**Quality Health Care for Persons with Developmental Disabilities: A Guide for Parents and Other Care Givers.** Pfaffinger, K., & Nelson, R. (1988).

This publication is a practical guide to health care for persons with disabilities. It includes specific suggestions on a wide range of relevant health care topics.

Available from Publications Office, Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, phone (612) 624-4512, fax (612) 624-9344.

**Quality Assurance: A Comprehensive, National Strategy for Health Care is Needed.** U.S. General Accounting Office. (1990).

This report on quality assurance focuses on health care systems. It provides several concepts, considerations and recommendations that are relevant to long-term care for persons with developmental disabilities.

Available from U.S. General Accounting Office, P.O. Box 6015, Gaithersburg, MD 20877.

**Family-Centered Care for Children with Special Needs**. Shelton, T., Jeppson, E., & Johnson, B. (1992).

Eight components are identified by parents and professionals as key elements of a family-centered multifaceted approach to health care. Each element is defined and examples of family-centered approaches, programs, and policies are provided.

Available through the Association for the Care of Children's Health, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814, phone (301) 654-6549.

**Saf-T**. Irwin Siegel Agency, Inc. (1995).

This booklet is intended for use by participants in vocational and supportive living programs. It was written to help people be safe while at work or home. In very simple language it presents safety rules for such topics as electricity, emergency evacuation, housekeeping, and many other topics.

Available from Irwin Siegel Agency, P.O. Box 309, Rock Hill, NY 12775-0309, phone (800) 622-8272.

# Consumer Choice

**Finding a Way Toward Everyday Lives: The Contribution of Person Centered Planning**. O'Brien, J. & Lovett, H. (1993).

This publication describes person-centered (personal futures) planning and its potential for creating better futures for people. The person-centered planning process is a method for discovering what people's desirable futures are and what it will take to make those futures possible.

Available through the Pennsylvania Department of Public Welfare, Office of Mental Retardation, PO Box 2675, Harrisburg, PA 17105-2675, phone (717) 787-3700.

**It's Never Too Early, It's Never Too Late.** Mount, B., & Zwernik, K. (1989).

This person-centered (personal futures) planning guidebook is written for family members and advocates, but others will also find it informative. It is intended as an introduction to the personal futures planning process and not an instruction manual.

Available through the Minnesota Bookstore, 117 University Avenue, Main Floor, St. Paul, MN 55155, phone (612) 297-3000.

**Planning Your Dreams: A Roadmap for Life After High School for Students with Developmental Disabilities**. Interagency Office on Transition Services, MN Department of Education. (1994).

This brochure provides a checklist for students with developmental disabilities who are planning for life after high school. Topics covered include training and learning after high school, employment, recreation and leisure, and independent living.

Available through the Interagency Office on Transition Services, 657 Capitol Square Building, 550 Cedar Street, St. Paul, MN 55101, phone (612) 297-2094.

**Policy Supporting Self-Determination in the Environments of Children with Disabilities.** In *Education and Training in Mental Retardation and Developmental Disabilities*, (30) 1, 3-13. Wehmeyer, M. (1995).

This article examines the importance of choice and self-determination for children with disabilities. It particularly focuses on physical environments in which such children live. Four pieces of legislation, including the Americans with Disabilities Act (ADA), are examined to identify opportunities created through legislation.

Available through The Council for Exceptional Children, Division on Mental Retardation and Developmental Disabilities, 1920 Association Drive, Reston, VA 22091-1589, phone (703) 264-9410. Also available on microform through University Microfilms International, phone (800) 521-3044.

# INDEX BY STATE


Alaska . . . . . IV-3, IX-5

Arizona . . . . . II-4, X-2, XIII-3

Arkansas . . . . . VIII-6

California . . . . . I-13, V-2, XI-3

Colorado . . . . . I-4, I-6, II-2, IX-6, XI-10

Connecticut . . . . . II-7, IX-11

Delaware . . . . . IV-2

Florida . . . . . XI-8

Georgia . . . . . VIII-7, IX-2, IX-8

Illinois . . . . . XI-9

Iowa . . . . . III-6, V-6

Kansas . . . . . VIII-5

Louisiana . . . . . VIII-9, IX-9

Maryland . . . . . V-7, XI-4, XIII-2

Massachusetts . . . . . I-2, XII-3

Michigan . . . . . IX-12, XI-5

Minnesota . . . . . I-7, II-4, II-5, II-6, II-9, VI-3, VIII-11, VIII-12, IX-3, IX-4, IX-14, X-3

Missouri . . . . . III-4

Nebraska . . . . . V-8

New Hampshire . . . . . III-2, IX-13

New York . . . . . I-9, III-3, III-7, VII-3, VIII-3

North Carolina . . . . . VII-4

North Dakota . . . . . VIII-2, VIII-10

Ohio . . . . . I-3, VIII-4, IX-10
Oklahoma . . . . . I-8, V-4
Oregon . . . . . II-8, IX-7
Pennsylvania . . . . . II-3, III-8, X-4, XII-2
Rhode Island . . . . . XI-6
South Carolina . . . . . I-10, I-12, V-5
Tennessee . . . . . IV-4
Utah . . . . . I-11
Vermont . . . . . I-5, III-10
Washington . . . . . V-3, VI-2
West Virginia . . . . . VII-2
Wisconsin . . . . . III-5, VIII-8, XI-7
Wyoming . . . . . II-4, III-9